

# **The experiences of family caregivers of persons with physical disabilities**

by

Noreth Muller-Kluits



*Thesis presented in fulfilment of the requirements  
for the degree of Master of Social Work in the  
Faculty of Arts and Social Science at Stellenbosch  
University*

Supervisor: Dr I Slabbert

December 2017

## **DECLARATION**

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (unless to the extent explicitly otherwise stated), that reproduction and publication thereof by University of Stellenbosch will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining and qualification.

December 2017

## ABSTRACT

Almost everyone will experience a form of impairment or disability some or other time in their lives. Different types of impairment could occur at any given moment. For example, parents might find out their baby was born with cerebral palsy, a person might be injured in a motor vehicle accident or a person who suffered a stroke is left paralysed on the one side. This disability can persist for years or even life-long, requiring family members to act as informal caregivers.

Living with a person with a disability can have significant effects on the family members. This unique shared experience can affect all aspects of family functioning in both a positive and a negative manner. Many previous research studies have investigated the needs of persons with disabilities but very few have focused on the family members who care for them.

The goal of this study was to gain a better understanding of the experiences of family caregivers of persons with physical disabilities. This goal was achieved by discussing the experiences of family caregivers of persons with physical disabilities from previous studies. The ecological perspective was utilised to explore the different social support needs and services of family caregivers of persons with physical disabilities. An analysis was done of the experiences of family caregivers of persons with physical disabilities regarding their support needs and the barriers they experience. Finally, relevant recommendations were made on how to improve social support to family caregivers of persons with physical disabilities.

It was decided to make use of Bronfenbrenner's ecological perspective when investigating the experiences of family caregivers of persons with physical disabilities. This perspective, which sees families as social environments, identifies four systems of a person's social environment: the micro-, meso-, exo- and macrosystem. The study also used the Parents' Supportive Care Needs Framework that identifies social, emotional, practical, physical, psychological and informational needs as parts of supportive needs of parents.

The research study used a qualitative approach with some elements of a quantitative approach with regard to identifying particulars of the participants. It used a combination of descriptive and exploratory research design. The reasoning of the research study was both deductive and inductive. The data collection was done by means of a semi-structured interview that was done with a sample of 20 participants of family caregivers of persons with physical disabilities

identified by the Tygerberg Association for Persons with physical disabilities in the Cape Town area. The research study used purposive sampling for 19 of the participants. One participant identified him/herself through snowball sampling.

During the empirical study, five themes were identified, namely support services used, support needs, general experiences of family caregivers, barriers experienced by family caregivers, and coping mechanisms of family caregivers. Although the research study had five different themes, these themes interlinked with one another in many cases, with a few exceptions. The first link was between support services used, positive experiences, and coping mechanisms used by family caregivers of persons with physical disabilities. The second was link between support needs, negative experiences, and barriers experienced by family caregivers of persons with physical disabilities. Throughout the research study, the researcher was able to identify many needs and barriers experienced by family caregivers of persons with physical disabilities but two main findings emerged: the lack of information on various aspects for family caregivers of persons with physical disabilities, and the need for more long-term care centres for persons with physical disabilities, especially adults.

Recommendations are aimed at overcoming the barriers experienced by family caregivers of persons with physical disabilities as well as at addressing the needs that were identified by them. Recommendations are made to certain service providers and there are also suggestions for future research. One of the main recommendations is that more research be conducted on similar topics. More similar studies on the experiences of family caregivers could be valuable to disability advocacy.

## OPSOMMING

Die meeste mense sal die een of ander tyd 'n vorm van gebrek of gestremdheid ervaar. Verskillende tipes gebreke kan op enige oomblik voorkom; byvoorbeeld ouers wat uitvind hul baba is met 'n serebrale gestremdheid gebore, 'n persoon wat tydens 'n motorongeluk beseer word, of 'n persoon wat 'n beroerte gehad het en aan die een kant verlam gelaat word. Die gestremdheid kan vir jare of selfs lewenslank duur, wat dan vereis dat familieleden as informele versorgers moet optree.

Om met 'n gestremdheid te lewe kan geweldige gevolge vir die hele familie inhou, insluitend ouers, broers en susters sowel as ander familieleden. Hierdie unieke ervaring kan die familie op verskeie maniere beïnvloed – beide positief en negatief. Etlike vorige navorsingstudies het al die behoeftes van persone met gestremdhede ondersoek, maar daar is nog nie baie op die familieleden wat hul versorg, gefokus nie.

Die doel van hierdie studie was om 'n beter begrip te kry van die ondervindings van familieversorgers van persone met fisiese gestremdhede. Hierdie doel is bereik deur onder meer die ondervindings van familieversorgers van persone met fisiese gestremdhede uit vorige studies te bespreek. Die ekologiese perspektief is gebruik om die verskillende ondersteuningsbehoeftes en -dienste te verken, deur die ondervindings van familieversorgers van persone met fisiese gestremdhede te analiseer ten opsigte van hul behoeftes en die struikelblokke wat hul ondervind. Voortvloeiend hieruit is relevante aanbevelings gemaak oor hoe om die maatskaplike ondersteuning aan familieversorgers van persone met fisiese gestremdhede te verbeter.

Tydens die navorsing is daar besluit om gebruik te maak van Bronfenbrenner se ekologiese perspektief. Hierdie perspektief sien die familie as 'n sosiale omgewing. Dit bied vier sisteme van die individu se omgewing, naamlik die mikro-, meso-, ekso- en makrosisteem. Die studie het ook gebruik gemaak van die Raamwerk vir die Ondersteuning van Versorgingsbehoeftes vir Ouers wat die sosiale, emosionele, praktiese, fisiese, sielkundige en inligtingsbehoeftes identifiseer as versorgingsbehoeftes vir ouers.

Daar is gebruik gemaak van 'n kwalitatiewe benadering met net sommige elemente van 'n kwantitatiewe benadering ten opsigte van die identifiserende besonderhede van die deelnemere. Dit het gebruik gemaak van 'n kombinasie van beskrywende en verkennende

navorsingsontwerp. Die beredenering in hierdie navorsingstudie was beide induktief en deduktief. Data is ingesamel deur gebruik te maak van 'n semi-gestruktureerde onderhoudskedule met 'n steekproef van 20 deelnemers wat familieversorgers van persone met fisiese gestremdhede was. Hulle is geïdentifiseer deur die Tygerbergse Vereniging vir Persone met Fisiese Gestremdhede in die Kaapstad-omgewing. Die navorsingstudie het gebruik gemaak van doelgerigte proefsteekneming met 19 van die deelnemers, een het hom/haar self het deur middel van sneeubal-proefneming geïdentifiseer.

Tydens die empiriese studie is vyf temas geïdentifiseer, naamlik ondersteuningsdienste gebruik, ondersteuningsbehoeftes, die algemene ondervindings van familieversorgers, die struikelblokke wat deur familieversorgers ervaar word en die hanteringsmeganismes van familieversorgers. Alhoewel die navorsingstudie vyf verskillende temas het, is daar in baie gevalle – met 'n paar uitsonderings – 'n verband tussen hierdie temas. Die eerste verband is tussen die ondersteuningsdienste, die positiewe ervarings en die hanteringsmeganismes wat gebruik is deur familieversorgers van persone met fisiese gestremdhede. Die tweede verband is tussen die ondersteuningsbehoeftes, die negatiewe ondervindings en die struikelblokke wat deur die familieversorgers ondervind word. Die navorser het deurgaans verskeie behoeftes en struikelblokke wat deur familieversorgers van persone met fisiese gestremdhede ondervind is, geïdentifiseer, maar twee hoofbevindings was duidelik – die gebrek aan inligting oor verskeie aspekte vir familieversorgers van persone met fisiese gestremdhede en die behoefte aan langtermynsorg vir persone met fisiese gestremdhede, veral volwassenes.

Aanbevelings is daarop gefokus om die struikelblokke te oorkom wat familieversorgers van persone met fisiese gestremdhede ervaar, sowel as om aan die behoeftes wat deur hulle geïdentifiseer is, te voldoen. Aanbevelings is aan sekere diensverskaffers gedoen en daar is ook voorstelle gemaak vir toekomstige studies. Een van die hoofaanbevelings is dat meer navorsing gedoen behoort te word oor soortgelyke onderwerpe. Dit kan gedoen word deur soortgelyke navorsing te onderneem oor die ondervindings van familieversorgers wat dan navorsing gebruik vir voorspraak vir mense met gestremdheid.

## ACKNOWLEDGEMENTS

I started my social work journey with the quote: “*No man is an island*” – referring to all the support networks that surround a single individual.

Throughout my studies, I came across another quote: “*It is not a lack of ability or opportunity that holds you back, it is only a lack of confidence in yourself.*” I would like to combine these two quotes and acknowledge the people that made it possible for me to continue having confidence in myself, and finally, being able to complete my studies successfully.

First, my husband, who has been my foundation of support in more ways than one: thank you for supporting me throughout the journey – helping me to realise my dreams and reminding me about it when I faced obstacles.

My family and family-in-law, for their continuous support throughout my studies: thank you for understanding the commitment it took to be able to do this.

My supervisor, Dr Slabbert, for all the assistance, continuous support and guidance throughout the process: I really respect and appreciate your expertise with regard to the end-result of this thesis.

Everyone that helped with the final editing and data verification of this thesis – thank you for your willingness to assist in this regard, it is highly appreciated.

Finally, the organisation and all the participants that were willing to be part of my research, without whom it would not have been possible to complete it: thank you very much.

To everyone else who played a part in this end-result: thank you very much for being part of the journey.

## TABLE OF CONTENTS

<b>DECLARATION.....</b>	<b>I</b>
<b>ABSTRACT.....</b>	<b>II</b>
<b>OPSOMMING.....</b>	<b>IV</b>
<b>ACKNOWLEDGEMENTS .....</b>	<b>VI</b>
<b>TABLE OF CONTENTS .....</b>	<b>VII</b>
<b>LIST OF FIGURES .....</b>	<b>XVI</b>
<b>LIST OF TABLES .....</b>	<b>XVII</b>
<b>LIST OF ACRONYMS AND ABBREVIATIONS .....</b>	<b>XVIII</b>
<b>GLOSSARY.....</b>	<b>XX</b>
<b>CHAPTER ONE: INTRODUCTION .....</b>	<b>1</b>
1.1.Preliminary study and rationale .....	1
1.2.Problem statement and focus .....	4
1.3.Research question .....	5
1.4.Theoretical point of departure.....	5
1.5.Goal and objectives.....	6
1.6.Research design and methodology.....	7
1.6.1. Literature review .....	7
1.6.2. Research approach .....	7
1.6.3. Research design .....	8
1.6.4. Sampling .....	8
1.6.5. Method/Instrument of data collection.....	10
1.6.6. Data quality verification .....	10
1.6.6.1.Credibility and authenticity .....	10
1.6.6.2.Transferability .....	10
1.6.6.3.Dependability .....	11
1.6.6.4.Conformality .....	11
1.6.7. Validity and reliability .....	11
1.6.8. Reflexivity.....	11
1.7.Data collection and processing procedure .....	12
1.7.1. Data collection .....	12
1.7.2. Qualitative data analysis and interpretation.....	12



1.8. Clarification of key concepts .....	12
1.8.1. Participant .....	12
1.8.2. Disability .....	13
1.8.3. Family caregivers .....	13
1.8.4. Ecological perspective .....	14
1.9. Research area .....	14
1.10. Ethical considerations .....	14
1.10.1. Ethical clearance .....	14
1.10.2. Ethical issues.....	14
1.10.2.1. Avoidance of harm.....	14
1.10.2.2. Voluntary participation .....	15
1.10.2.3. Informed consent.....	15
1.10.2.4. Confidentiality .....	16
1.10.2.5. Compensation.....	16
1.10.2.6. Debriefing of participants .....	16
1.10.2.7. Publication of findings .....	17
1.11. Limitations of the present study.....	17
1.12. Presentation.....	18
<b>CHAPTER TWO: THE NATURE AND SCOPE OF FAMILY CAREGIVERS WHEN CARING FOR A PERSON WITH A PHYSICAL DISABILITY .....</b>	<b>20</b>
2.1. Introduction.....	20
2.2. Overview of caring for a person with a physical disability .....	20
2.3. Scale of disabilities .....	22
2.3.1. The meaning of ‘physical disability’ .....	22
2.3.2. Different onsets of physical disability .....	22
2.3.3. Prevalence of different disabilities.....	23
2.3.3.1. Prevalence of disability worldwide .....	23
2.3.3.2. Prevalence of disability nationwide (South Africa) .....	23
2.3.3.3. Prevalence of disability in the Western Cape.....	25
2.4. Caring for a person with a physical disability .....	25
2.4.1. Role of family in caring for a person with physical disabilities .....	27
2.5. Experiences of family caregivers when adapting to care for persons with physical disabilities .....	28

2.5.1. Feelings related to grief .....	29
2.5.2. Negative experiences .....	31
2.5.2.1. Stress .....	34
2.5.3. Positive experiences .....	34
2.6. Barriers experienced by family caregivers of persons with physical disabilities in accessing resources .....	35
2.6.1. Health care issues.....	35
2.6.1.1. Health care financing .....	35
2.6.2. Education issues .....	35
2.6.3. Employment issues .....	37
2.6.3.1. Employment for persons with physical disabilities .....	37
2.6.3.2. Fewer opportunities for employment and financial issues for caregiver .....	37
2.6.4. Establishment and implementation of policies and legislation .....	38
2.6.5. Funding of non-governmental programmes .....	39
2.6.6. Social barriers .....	40
2.6.7. Physical barriers .....	40
2.6.8. Respite services .....	40
2.6.9. Physical health issues .....	41
2.6.9.1. Greater difficulty as family member(s) age .....	42
2.7. Coping mechanisms used by family caregivers for persons with physical disabilities ....	45
2.8. Conclusion .....	45
<b>CHAPTER THREE: THE SUPPORT NEEDS AND RESOURCES AVAILABLE TO FAMILY CAREGIVERS OF PERSONS WITH PHYSICAL DISABILITIES .....</b>	<b>46</b>
3.1. Introduction.....	46
3.2. Support needs of persons with physical disabilities .....	46
3.2.1. Previous research findings on support needs of family caregivers .....	47
3.2.2. Parents' support care needs framework .....	47
3.2.2.1. Emotional needs .....	50
3.2.2.2. Practical needs.....	50
3.2.2.3. Physical needs .....	50
3.2.2.4. Informational needs.....	50
3.2.2.5. Social needs.....	51
3.2.2.6. Spiritual needs.....	51

3.3. Overview of Bronfenbrenner's ecological perspective.....	52
3.3.1. Microsystem .....	53
3.3.2. Mesosystem.....	53
3.3.3. Exosystem .....	53
3.3.4. Macrosystem .....	54
3.4. Social support available to family caregivers of persons with physical disabilities at the different levels presented by the ecological perspective.....	54
3.4.1. Microsystem .....	55
3.4.2. Mesosystem.....	56
3.4.2.1. Health-care professionals .....	57
3.4.3. Exosystem .....	57
3.4.3.1. Special care centers .....	58
3.4.3.2. Special schools .....	59
3.4.3.3. Full-service schools.....	59
3.4.4. Macrosystem .....	59
3.4.4.1. Disability benefits .....	60
a) Care Dependency Grant .....	60
b) Assistive devices .....	61
c) Personal Income Tax benefits .....	61
3.4.4.2. Cultural norms and attitudes .....	62
3.4.4.3. Policies and legislation .....	63
a) Convention on the Rights of Persons with disabilities .....	63
b) International Classification of Functioning, Disability and Health .....	63
c) Constitution of the Republic of South Africa .....	63
d) The White Paper on Integrated National Disability Strategy, South Africa .....	64
e) Integrated Service Delivery Model, South Africa .....	64
f) Education White Paper 6, South Africa .....	65
g) White Paper for Social Welfare, South Africa .....	65
3.4.4.4. Education system .....	67
3.4.4.5. Health care .....	67
3.5. Conclusion .....	68

## **CHAPTER FOUR: ANALYSIS OF EXPERIENCES OF FAMILY CAREGIVERS OF PERSONS WITH PHYSICAL DISABILITIES IN THE EMPIRICAL STUDY ..... 69**

4.1. Introduction .....	69
4.2. Research methodology.....	69
4.2.1. Research question .....	69
4.2.2. Goals and objectives .....	70
4.2.3. Research approach .....	70
4.2.4. Research design .....	71
4.2.5. Research instrument .....	71
4.2.6. Research sample .....	72
4.2.7. Data collection and analysis .....	73
4.2.8. Data quality verification .....	73
4.3. Participants' identifying particulars .....	74
4.3.1. Gender of participants .....	74
4.3.2. Age group of participants .....	75
4.3.3. Living area of participants .....	76
4.3.4. Marital status of participants.....	78
4.3.5. Employment status of participants.....	79
4.3.6. Relationship participant has towards person with a physical disability .....	81
4.3.7. Age group of care dependant(s) of participants .....	82
4.3.8. Onset of disability of dependant(s) of participants .....	84
4.3.9. Type of physical disability of dependant(s) of participants .....	85
4.4. Data collected from participants during empirical study.....	87
4.4.1. Theme 1: Support services used (available to) by family caregivers of persons with physical disabilities in accordance to Bronfenbrenner's Model .....	88
4.4.1.1. Sub-theme 1.1: Microsystem .....	88
a) Parental subsystem.....	88
b) Spousal subsystem .....	89
c) Sibling subsystem .....	89
4.4.1.2. Sub-theme 1.2: Mesosystem .....	91
a) Extended family .....	91
b) Friends .....	92
c) Professionals .....	92
4.4.1.3. Sub-theme 1.3.: Exosystem .....	94

a) Educational institutions .....	94
b) Health facilities.....	95
c) Welfare organisations and other community facilities .....	96
4.4.1.4. Sub-theme 1.4.: Macrosystem .....	98
a) South African health-care system .....	98
b) Education system .....	99
c) Disability benefits .....	100
4.4.2. Theme 2: Support needs of family caregivers of persons with physical disabilities in accordance with Bronfenbrenner's model .....	101
4.4.2.1. Sub-theme 2.1: Microsystem .....	102
4.4.2.2. Sub-theme 2.2: Mesosystem .....	103
4.4.2.3. Sub-theme 2.3: Exosystem .....	104
a) Lack of schools and training institutions .....	105
b) Lack of long-term care centres .....	106
c) Overcrowded health-care facilities .....	108
d) Lack of public transport systems within communities .....	109
e) Lack of recreational groups for persons with disabilities .....	110
f) Lack of information .....	111
4.4.2.4. Sub-theme 2.4: Macrosystem .....	112
a) Policies and legislation .....	113
b) Disability-friendly employment .....	113
4.4.3. Theme 3: General experiences of family caregivers of persons with physical disabilities .....	114
4.4.3.1. Sub-theme 3.1: Feelings of grief .....	114
4.4.3.2. Sub-theme 3.2: General positive experiences .....	115
4.4.3.1. Sub-theme 3.3: General negative experiences .....	116
4.4.4. Theme 4: Barriers experienced by family caregivers in taking care of person(s) with physical disability.....	117
4.4.4.1. Sub-theme 4.1: Lack of support .....	117
a) Community accessibility and safety .....	118
b) Accessing services .....	119
c) Personal home accessibility .....	120
4.4.4.2. Sub-theme 4.2: Caregiver burden issues .....	121
a) Physical health issues .....	121

b) Personal isolation .....	122
c) Lack of respite services .....	122
d) Employment issues of caregivers .....	124
e) Financial issues .....	125
f) Emotional health issues .....	126
g) Giving up on own aspirations (caregiver) .....	127
4.4.4.3. Sub-theme 4.3: General issues with person(s) with disability/-ies.....	128
a) Behaviour of person(s) with disability/-ies .....	128
b) Being blamed by person(s) with disability/-ies .....	129
4.4.5. Theme 5: Coping mechanisms used by family caregivers in taking care of persons with physical disabilities .....	130
4.4.5.1. Sub-theme 5.1: Outings .....	130
4.4.5.2. Sub-theme 5.2: Recreational activities and hobbies .....	131
4.4.5.3. Sub-theme 5.3: Socialising .....	132
4.4.5.4. Sub-theme 5.4: Personal time .....	133
4.5. General observations on the experiences of family caregivers of person with physical disabilities from the empirical study.....	134
4.5.1. The link between the different themes .....	134
4.5.1.1. The link between support services used, positive experiences and coping mechanisms used by family caregivers of persons with physical disabilities .....	134
4.5.1.2. The link between support needs, negative experiences and barriers experienced by family caregivers of persons with physical disabilities.....	135
4.5.2. Connections with a previous study .....	137
4.5.3. Main topics identified .....	137
4.5.4. Identified topics that did not have many previous studies' finding to compare with ..	138
4.6. Conclusion .....	138
<b>CHAPTER FIVE: CONCLUSION .....</b>	<b>139</b>
5.1. Introduction.....	139
5.2. Lessons learned from this study.....	139
5.3. Recommendations .....	140
5.3.1. Research method and design .....	141
5.3.1.1. Summary.....	142
5.3.1.2. Recommendation for future studies.....	142

5.3.2. Identifying particulars .....	142
5.3.2.1. Summary.....	142
5.3.2.2. Recommendation for future studies.....	142
5.3.3. Theme 1: Support services used .....	143
5.3.3.1. Summary.....	143
5.3.3.2. Recommendation for future studies.....	143
5.3.4. Theme 2: Support needs .....	144
5.3.4.1. Summary.....	144
5.3.4.2. Recommendation to address support needs.....	144
a) Professional support (formal support).....	144
b) Peer support groups.....	145
c) Schools and training institutions .....	145
d) Health facilities that are not overcrowded .....	145
e) Lack of long-term care centres .....	145
f) Recreational support groups for persons with disabilities (day-care centers) .....	146
g) Transport for persons with disabilities.....	146
h) Information on resources and services available .....	146
i) Medical information on caring for persons with disabilities .....	146
j) Educational information for special needs of persons with disabilities ...	146
k) Information regarding policies and legislation on persons with disabilities and their families.....	147
l) Disability-friendly employment.....	147
5.3.4.3. Recommendation for future studies.....	147
5.3.5. Theme 3: General experiences of family caregivers .....	147
5.3.5.1. Summary.....	148
5.3.5.2. Recommendation for future studies.....	148
5.3.6. Theme 4: Barriers experienced by family caregivers.....	148
5.3.6.1. Summary.....	148
5.3.6.2. Recommendation to overcome barriers.....	148
a) Community accessibility and safety.....	149
b) Accessing services .....	149
c) Personal home accessibility .....	149
d) Lack of respite care services .....	149

e) Employment issues for caregivers.....	150
f) Financial issues .....	150
g) Behaviour of person with disabilities .....	150
5.3.6.3. Recommendation to overcome barriers .....	150
5.3.7. Theme 5: Coping mechanism of family caregivers .....	151
5.3.7.1. Summary.....	151
5.3.7.2. Recommendation for future studies.....	151
5.3.8. Final recommendations for future studies.....	152
<b>REFERENCES.....</b>	<b>153</b>
<b>ANNEXURES.....</b>	<b>162</b>
Annexure A: REC Approval Notice .....	162
Annexure B: Consent form for research through Tygerberg Association for Persons with (Physical) Disabilities .....	163
Annexure C: Consent form for participants (English).....	164
Annexure D: Consent form for participants (Afrikaans) .....	168
Annexure E: Example of questionnaire (English) .....	172
Annexure F: Example of questionnaire (Afrikaans).....	176
Annexure G: Research Information sheet (Afrikaans/English).....	180
Annexure H: Example of Member checking verification (English/Afrikaans).....	182
Annexure I: Independent coder theme verification .....	183
Annexure J: Declaration of language practitioner .....	184



## LIST OF FIGURES

Figure 4.1. Gender of participants .....	75
Figure 4.2. Age group of participants .....	76
Figure 4.3. Participants in different Cape Town suburbs .....	77
Figure 4.4. Socio-economic conditions of areas related to this study (%) .....	78
Figure 4.5. Participants' marital status .....	79
Figure 4.6. Participants' employment status.....	80
Figure 4.7. Relationship of participants to person with a physical disability .....	81
Figure 4.8. Age group of participants' dependant(s) .....	83
Figure 4.9. Onset of disability of participants' dependant(s).....	83
Figure 4.10. Type of disability of participants' dependant(s).....	86

## LIST OF TABLES

Table 3.1. Type of assistance and support services for persons with disabilities and their families.....	48
Table 3.2. Framework for support needs of parents of children with a rare disease .....	49
Table 4.1. Themes, sub-themes and categories identified in research study .....	87

## LIST OF ACRONYMS AND ABBREVIATIONS

ADL(s)	Activities of daily living
AIDS	Acquired immunodeficiency syndrome
APD	Association for Persons with (Physical) Disabilities
BEE	Black economic empowerment
CDG	Care dependency grant
CP	Cerebral palsy
CSWE	(American) Council on Social Work Education
DBE	Department of Basic Education (South Africa)
DoH	Department of Health (South Africa)
DHIS	District health information system
DWCPD	Department of Women, Children and Persons with Disabilities (South Africa)
GP	General practitioner
HIV	Human immunodeficiency virus
HPCSA	Health Professions Council of South Africa
ICF	International classification of functioning, disability and health
NGO	Non-governmental organisation
NSH	New Somerset Hospital
PwD	Person with a disability
REC	Research Ethics Committee
RCWMCH	Red Cross War Memorial Children's Hospital
RDP	Reconstruction and Development Programme
RSA	Republic of South Africa
SARS	South African Revenue Service
SASSA	South African Social Security Agency
SB	Spina bifida
SCA	Spinocerebellar ataxia
SCI	Spinal cord injury
SIAS	Screening, identification, assessment and support
SACSSP	South African Council for Social Service Professions
TVET	Technical Vocational Education and Training
UNICEF	United Nations International Children's Emergency Fund

USA	United States of America
WC	Western Cape
WHO	World Health Organization
WWE	World Wrestling Entertainment, Inc.

## GLOSSARY

### TYPES OF DISABILITIES

Blindness	When a person sees nothing, he/she is considered blind.
Cerebral Palsy	Cerebral palsy means ‘brain paralysis’. Certain parts of the brain are damaged; mainly parts that control movements.
Deafness	When a person cannot hear at all, he/she is considered deaf.
Hearing impairment	When a person can hear to a certain extent only, he/she has a hearing impairment.
Hemiplegia	This is a substantial loss of function on one side of the body (arm or leg); it often occurs due to a stroke or as a result of epilepsy.
Paraplegia	Paraplegia refers to the loss of controlled movement and feeling in the legs only.
Quadriplegia	Quadriplegia refers to the loss of controlled movement and feeling from the neck or chest down. All four limbs (arms and legs) are affected.
Spina Bifida	Spina bifida literally means “split spine”. Spina bifida occurs when the spinal column of a foetus in the womb does not close all the way.
Spinocerebellar Ataxia	Spinocerebellar ataxia refers to a group of hereditary ataxias that are characterised by degenerative changes in the part of the brain related to the movement control (cerebellum), and sometimes in the spinal cord.
Spinal Cord Injury	Spinal cord injury is usually caused by an accident that breaks or severely damages the central nerve cord in the neck or back known as the spinal cord.
Stroke	Strokes occur when blood flow to an area of the brain is interrupted resulting in death of brain tissue. It can result in hemiplegia (paralysis on one side of the body) or hemiparesis (weakness on one side).
Triplegia	Triplegia is a medical condition characterised by the paralysis of three limbs.

## Visual impairment

Visual impairment can be mild, moderate, or severe. Some people can only see the difference between light and dark or day and night, but cannot distinguish any shapes.

## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.1 PRELIMINARY STUDY AND RATIONALE**

Almost everyone will experience a form of impairment or disability (either temporary or permanent) in their lifetime (Hartley, Ilagan, Madden, Officer, Posarac, Seelman, Shakespeare, Sipos, Swanson and Thomas, 2011:3). Various forms of impairment could occur at any given moment; for example, a baby is born with Down syndrome, a soldier loses his leg at war or a person suffers a stroke and is left paralysed on the one side. Kress and Herridge (2012:340) pointed out another way that people can acquire a physical disability, namely after a critical illness. This disability can persist for years or even life-long, requiring assistance from family caregivers.

Disability does not only affect the disabled person but also has an impact on their support network, that is, friends and family. When a family member has a disability, whether a physical disability, psychological illness, chronic or life-threatening illness, it is the family that generally provides care. According to Blanes, Carmagnani and Ferreira (2007:401), about 90% of persons with chronic diseases are cared for by their relatives. Family members also generally live with the patient. In their study, focusing on caregivers of persons with paraplegia, it was found that, besides the spouses (26.6%), sisters (23.4%) and mothers (18.3%) also act as caregivers. In addition, there will also be a prevalence of skipped-generation guardians, that is, grandparents. In an earlier study of persons with spinal cord injuries (SCI), De Vivo and Fine (1985:501–504) found that the caregiver spends an average of 11.3 hours per day caring for the person with SCI and is also responsible for housekeeping tasks and the care of other dependent family members.

To understand the needs of family caregivers of persons with physical disabilities, it is important to look first at the prevalence of disability and the needs of persons with disabilities. The World Report on Disability describes different types of assistance and support services that persons with disabilities and their families may need. These include community support, residential support services, respite services to give caregivers breaks, education and employment support, communication support, information and

advice services, as well as assistance animals that would be used especially by visually impaired people (Hartley et al., 2011:139). The World Report on Disability serves as a precedent for this study.

The increasing rate of disability and the need for most disabled persons to rely on family members for support has led to a growing need for support for the families of persons with disabilities who act as caregivers. Parents, professionals, and academic researchers have claimed that families face unique needs if one of the family members has a disability (Leiter, 2004:6).

Redfern (2013:20) points out that in South Africa specifically, there is a lack of research and no recent prevalence studies in urban and peri-urban contexts regarding disability. It must be emphasised that national surveys in South Africa are likely to be significantly under-representing the burden of childhood disability across the country.

Simplican, Leader, Kosciulek and Leahy (2015:27) comment that there also seems to be a lack of previous research that analyses the support needs of family caregivers looking after a person with a physical disability. The lack of research on this topic served as the rationale for the study. Most people with intellectual and developmental disabilities live with their families, yet little research has examined their level of social inclusion. More attention should be given to the conditions that affect families' opportunities for and obstacles to social inclusion, such as family culture, socio-economic status, and social capital.

In a study in Butterworth in the Eastern Cape, Dingana (2012:142) focused on the needs of people with physical disabilities and the accessibility of resources available to them. Although her research focused on the needs of the person with the disability, she also considered the needs of the caregivers of persons with physical disabilities. This study clearly showed that some people with physical disabilities need to have constant caregivers. However, service providers tend to not consider them as important.

Goldner and Drentea (2009:499) found that families care for disabled relatives for many reasons, including choice, a sense of responsibility, and financial necessity. They also



questioned what impact caregiving has on the caregiver and pointed out that most research shows that family caregivers often suffer negative outcomes. Family members may experience stress, resentment, depression, ambivalence, anger, denial, depression, embarrassment, fear of stigma, grief, guilt, shock and withdrawal (Goldner and Drentea, 2009:499; Gull and Nizami, 2015:144). Another factor, according to Jeong, Myong and Koo (2015:619) is that raising and taking care of a child with a physical disability is a full-time responsibility that either requires one of the parents to stay home or for parents to hire a private caregiver. The importance of analysing the effect of caregiving on the caregiver to understand how disability affects the entire family, not just the person who is disabled, has also been emphasised by Goldner and Drentea (2009:499).

Most studies assume parents (especially mothers) are the primary caregivers of persons with disabilities and therefore references to previous research might refer to parents only. In this study, however, the focus was on the adult family member (whether parent or other family member) who takes care of the person with the physical disability.

As a social worker that worked with persons with disabilities and their families in the Overstrand area, and through personal experience of knowing families with similar obstacles, it has always been clear to the researcher that there is a lack of ongoing support for caregivers of persons with disabilities. Although there are more facilities, health professionals and technological advances than a few decades ago, one thing still seems to remain absent: on-going support to family caregivers on a very regular basis and not just when there is a problem. Ongoing support could decrease feelings of helplessness and hopelessness. In several cases during service delivery in the Overstrand area, parents indicated that they felt overwhelmed by the challenge of raising a child with a disability and due to lack of service support they rarely had the opportunity to gain the skills to cope with the situation. The researcher agrees with Collins, Swartz, College and Jefferson (2011:1309–1317) who found that further research is needed to identify strategies to offset caregiver stress, depression, and poor health outcomes.

It is clear, based on the foregoing, that there is a great need for more research. The researcher decided to investigate the support needs of caregivers of persons with physical

disabilities to clarify what the needs are and to advocate for more awareness and action towards the required support. These persons with disabilities could either be children born with a disability and who later grew up to be adults with disabilities or adults with disabilities that had acquired a disability. The study aimed to investigate the experiences of family caregivers of persons with physical disabilities.

## **1.2 PROBLEM STATEMENT AND FOCUS**

Many previous research studies have investigated the needs of persons with disabilities but not many have focused the family members who care for them. This research study focused on the experiences of the family caregivers of persons with physical disabilities. Very little previous research has been conducted over the last five years on the social support of family caregivers of persons with physical disabilities. The Nexus research database (Nexus, 2016) shows fewer than 10 research studies with a similar focus on the experiences, and especially the needs, of family caregivers of persons with physical disabilities in the past ten years.

Vermaak (2016:8) identified seven previous studies that have been conducted on persons with spinal cord injuries (a type of physical disability) in South Africa, mostly focusing on the experiences of the person him- or herself or the effect it has on South Africa. This further emphasises the lack of research on the family caregivers. Spinal cord injuries were only one type of physical disability that was relevant to this study. This study sought to investigate how the findings from previous studies correlate with the findings from this study.

Due to the lack of relevant previous studies, it is evident that there is a gap in the research field. A study of this nature is therefore beneficial to the social work profession to gain a better understanding of the experiences of family caregivers of persons with physical disabilities.

## **1.3 RESEARCH QUESTION**

Given and Munhall (2008:787) states that research questions form an important part within qualitative research. It can indicate the initial theoretical and methodological orientations of the researcher without it having to be done in an explicit manner.

The study originated from the research question:

*What are the experiences of family caregivers of persons with physical disabilities?*

#### **1.4 THEORETICAL POINT OF DEPARTURE**

The World Report on Disability (Hartley et al., 2011:36) states that the functioning of a child should be viewed in the context of the family and the social environment. Models of disability have generally been used to illuminate the experiences of disabled adults. Four major models of disability are used in service delivery to children with a disability, namely the medical, social, transactional and the ecological or systems model. The strength of the ecological or systems model of disability is that it puts the child with a disability in the context of an environment that could generate developmental changes (Bricout, Porterfield, Tracey and Howard, 2004:46-54).

Taking this statement into consideration, it was decided to make use of the ecological perspective when investigating the needs of family caregivers of persons with physical disabilities. The ecological perspective sees families as social environments which could be improved through public intervention. An ecological perspective reinforces the importance of the need for an equal focus on both the person and the environment (Edmonds, 2003:757).

Bronfenbrenner's model of community levels, later known as the ecological perspective, identifies four systems of a person's social environment. These are the micro-, meso-, exo- and macrosystem (Visser, 2007:25).

The microsystem consists of interpersonal relations experienced by a person in a given face-to-face setting (Edmonds, 2003:757). The microsystem refers to the family caregivers and their closest relationships with other people, for example other family members (Russell, 2003:145). The mesosystem is comprised of the interrelationships among two or more settings in which the person actively participates (Edmonds, 2003:757). The set of links between microsystems is known as the mesosystem (Nash, Munford and O'Donoghue, 2005:37). The relevant persons could be professionals and other people with whom family caregivers interact regularly to take care of the persons with physical disability. The exosystem consists of the interconnections between the

micro- and mesosystems (Chetkow-Yanoov, 1997:11; Visser, 2007:25). An example is the government and welfare programmes (Edmonds, 2003:757). Lastly, the macrosystem is the wider system of social ideology and the organisation of social institutions, including cultural values (Scileppi, Teed and Torres, 2000:47; Visser, 2007:25). Bronfenbrenner defines the macrosystem as the societal blueprint for a particular culture, subculture, or other broader context (Edmonds, 2003:757). Previous studies have put the individual with the disability in the context of these systems. In this study, the family caregivers of the person with the disability were put in the context of these four systems. By doing this, the research study was provided with a holistic overview of the needs of caregivers in more than one aspect of their lives.

The study also used the Parents' Supportive Care Needs Framework discussed in Pelentsov, Laws and Esterman (2015:489) that identifies that social, emotional, practical, physical, psychological and informational needs as part of supportive needs of parents. Although their study focused on the support needs of parents with children of a rare disease instead of physical disabilities specifically, it was a useful guide in predicting the possible outcomes of the study.

## **1.5 GOAL AND OBJECTIVES**

The goal of this study was to gain a better understanding of the experiences of family caregivers of persons with physical disabilities. This goal was achieved by means of the following objectives:

- To discuss the experiences of family caregivers of persons with physical disabilities from previous research and studies;
- To use the ecological perspective to explore the different social support needs and services of family caregivers of persons with physical disabilities;
- To analyse the experiences of family caregivers of persons with physical disabilities on the social support services used, their support needs, general experiences, barriers and coping mechanisms; and
- To make relevant recommendations on how to improve social support to family caregivers of persons with physical disabilities.

## **1.6 RESEARCH DESIGN AND METHODOLOGY**

The research design and methodology can be broken down into the literature review, research approach, research design, sampling, instrument of data collection, validity, reliability and reflexivity, as presented below.

### **1.6.1 Literature review**

A literature review has many functions, especially within qualitative research. It serves to get an understanding of the issue at hand. It also helps to identify certain similarities and differences between previous studies and current issues (De Vos, Strydom, Fouche and Delport, 2011:109). Another key function of a literature review is to identify gaps in knowledge or weaknesses in previous studies (Bless, Higson-Smith and Kagee, 2006:24).

The last function mentioned above seemed to play a cardinal role as a review of previous research done. Addressing the support needs of parents of persons with physical disabilities is not a topic that has been researched extensively in the past. Most of the previous research that was done focused on disability prevalence, the use of support services or the perceptions of the disabled person him- or herself on their support needs.

The purpose of conducting a literature review in this research study was to identify previous research on the experiences of family caregivers of persons with physical disabilities in terms of their needs, barriers and the services they use as well as how the ecological perspective was used with regard to the needs of caregivers. The findings from such previous research guided the researcher in collecting information on what family caregivers' experiences are regarding this matter during the empirical part of this study.

### **1.6.2 Research approach**

The research study used a qualitative approach with some elements of a quantitative approach with regard to details of the participants. The qualitative approach of the study provided the research study with different 'case studies' as every participant would be able to provide comprehensive information on their experiences.

The decision to use a qualitative approach to this research project was led by the belief that qualitative research is a valuable approach in social work. In 1994, the Council on Social Work Education (CSWE) in the USA insisted that qualitative research methods must be taught at both bachelor's and master's level social work programmes (Drisko, 2013:1).

### **1.6.3 Research design**

The design used in this research study was a combination of descriptive and exploratory research. According to De Vos et al. (2011:95-96), the aim of exploratory research is to gain insight into a phenomenon, situation, community or individual. Descriptive research can be described as a more intensive analysis of phenomena to gain a more comprehensive description (Rubin and Babbie, 2005:125).

A combination of deductive and inductive reasoning was used in this research study. Deductive reasoning takes place when the reasoning moves from general to specific findings. It moves from logically and theoretically expected findings to test whether the expected patterns occur. Inductive reasoning, on the other hand, occurs when reasoning moves from the specific to the general (De Vos et al. 2011:48-49).

### **1.6.4 Sampling**

The research project made use of 20 participants with whom interviews were conducted. The planned method of sampling was purposive sampling where a clear definition of the population and intended sample is very important. The concept of purposive sampling includes the broad process of defining the population as well as all the potential aspects or characteristics that could be included in order to identify the sample (Given and Munhall, 2008:799). Due to the lack of participants, one of the participants was identified through snowball sampling. Snowball sampling is usually used when there is limited access to appropriate participants (De Vos et al., 2011:233). Snowball sampling could lead to a selection of various participants but was only needed for one participant in this study.

De Vos et al. (2011:110) differentiate between the concepts universe, population and sample. According to these authors, the universe includes all possible subjects that

possess all the characteristics that the researcher is interested in for the study to be conducted. The population refers to the total set out from which the individuals for the study are chosen whilst the sample refers to the subjects chosen to participate fully in the study.

The method for sample selection was first to get permission from the organisation that delivers services to persons with disabilities and their families and asking them to identify possible participants. Tygerberg APD agreed to work in partnership with the researcher for this research project. After meeting with the organisation, they suggested that they set up the possible participants and send the contact details to the researcher. This method was used for 19 participants with one participant that was identified by means of snowball sampling.

For the study, the universe of sampling included all the family members of persons with disabilities. The population was family caregivers of persons with disability identified by the Tygerberg APD in the Cape Town area. The criteria for inclusion for the sample were the following:

- The participant must be a family caregiver of a person with a physical disability.
- The participant must be caring for the person with the physical disability that is not due to old age.
- The participant must be living in the Cape Town area.
- The participant should be able to understand and speak either Afrikaans or English.

#### **1.6.5 Method/instrument of data collection**

The data collection was done by means of a semi-structured interview schedule. This instrument, according to De Vos et al. (2011:352), is mainly used to gain a perspective of the participant's perception of the research topic at hand. For this study, the interview schedule was done in either Afrikaans (see Annexure F) or English (see Annexure E), depending on the preferred language of the participant.

This interview schedule consisted of open-ended questions except in the section regarding the interviewee's profile, where a combination of closed-ended questions, multiple choice and dichotomous questions was used. Researchers use an open-ended

question to allow them to select how they adapt to the research topic (Given and Munhall, 2008:583). For this study, a voice recorder was used to audio tape the interviews after consent from participants was first obtained. Thereafter, these interviews were transcribed. Field notes were also made during interviews to assist the researcher with the analysis of interviews.

Oliver, Serovich and Mason (2005:1273) conducted a study on the constraints and opportunities related to interview transcription. They state that transcription can have a significant effect on how participants of a study are understood in terms of what they share and the conclusions that are drawn from that. They explain that transcription practices have two main methods, namely naturalism and denaturalism. Naturalism refers to transcription that is done with as much detail as possible, where the language represents the real world. Denaturalism refers to the removal of unique elements of speech such as pauses and non-verbal factors which suggest that within speech there are certain meanings and perceptions. This research study made use of the denaturalistic method of transcribing.

#### **1.6.6 Data quality verification**

De Vos et al. (2011:419), state that credibility and authenticity, transferability, dependability and conformability must be considered when establishing the candour of the qualitative research study.

##### **1.6.6.1 Credibility and authenticity**

The goal of establishing credibility and authenticity is to ensure that the subject has been accurately identified and described. The researcher should question whether there is a match between the participants' views and the researcher's reconstruction and representation of them (De Vos et al., 2011:419-420). This was done through member checking (see Annexure H) where some of the participants were given the transcripts of their interviews to confirm whether this was an accurate depiction of their interviews.

##### **1.6.6.2 Transferability**



In order to assess the quality of the research study, the researcher must ask whether the study can be transferred from one specific situation to another (De Vos et al., 2011:420). The wide-spread identifying particulars of the participants discussed in Chapter Four could influence the transferability of the study in a positive way.

#### 1.6.6.3 Dependability

The researcher must assess whether the research process was logical, well-documented and audited (De Vos et al., 2011:420). The research process has been discussed in section 1.6.1 to 1.6.5. This process was also explained to the participants in the Consent to Participate forms (see Annexures C and D).

#### 1.6.6.4 Conformability

De Vos et al. (2011:346) explain conformability as the alternative for objectivity. It implies that the study's findings could be confirmed by another. Conformability of this study was ensured by means of literature control in Chapter Four and by engaging an independent coder who confirmed the themes identified for this research study (see Annexure I).

### 1.6.7 **Validity and reliability**

Drisko (2013:29) advises that social workers should keep their profession's values and ethical standards in mind when selecting a sample. When qualitative research focuses on the needs of individuals and the services they receive, it is particularly compelling. Drisko further believes that including vulnerable people in a sample could provide an opportunity to empower them and recognise their expertise. The researcher in this current research project agreed with Drisko as this research sought to identify the needs of parents and give voice to their concerns and their perceptions and suggestions.

### 1.6.8 **Reflexivity**

Reflexivity refers to the levels of self-reflection that allow us to develop ourselves while understanding how we influence and construct the world around us. Reflexivity allows us to explore ourselves as both products and creators of social order. The nature of who we are, as well as our interactions within research settings, can shape research processes and outcomes. Reflexivity in research is the recognition of this dilemma as

well as an attempt to work towards valid interpretations that take the impact of researchers into account (O’Leary, 2007:223). The researcher kept in mind that objectivity was key to the success of the research and limited subjective reflection to the final discussion of findings.

## **1.7 DATA COLLECTION AND PROCESSING PROCEDURE**

The data collection and processing procedure for this study was comprised of qualitative data collection and interpretation.

### **1.7.1 Data collection**

Data for the empirical study was collected through semi-structured interviews with the 20 participants. According to De Vos et al. (2011:352), this type of interview schedule is mainly used to gain a perspective of the participant’s perception of the research topic at hand. The themes of the interview schedules related to the themes from the literature review gathered from previous studies. The combination of these two data sources formed the basis of the data used for this study.

### **1.7.2 Qualitative data analysis and interpretation**

Babbie (2007:378) describes qualitative data analysis as a non-numerical analysis and interpretation of observations to discover underlying meanings and patterns of relationships. This study collected the information from the different interviews and identified the main discussion points (themes) as well as the differences and connections between the different participants’ answers. This data was then discussed and analysed further in terms of previous research and possible future research, as indicated in Chapter Four.

## **1.8 CLARIFICATION OF KEY CONCEPTS**

This study refers to various concepts. To allow for a better understanding of the content of the study, the following concepts are clarified below.

### **1.8.1 Participant**

Participants are sometimes referred to as subjects, respondents, interviewees, focus group members or informants. Participants contribute data to research through

questionnaires, interviews, experiments, personal health records, narratives, focus groups, and direct observation (Given and Munhall, 2008:598-599). For this study people with whom interviews were done are referred to as participants.

### **1.8.2 Disability**

There are various definitions for disability (Freedman, 2008:334). For this study, the definition of disability articulated by the World Health Organization (WHO) was used:

*“Disability is an umbrella term for impairments, activity limitations or participation restrictions ‘conceiving’ a person’s functioning and disability . . . as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors, including the social, attitudinal, and physical environments and personal attributes”*(WHO, 2001, cited in Freedman, 2008:33).

Koopman (2003:6) uses the term ‘people with disability/-ies’ instead of ‘disabled people’. This researcher agrees with the author that the person with a disability is a person first and then disabled. Koopman further points out that by using the labels ‘disabled’ the focus is placed exclusively on what is different about individuals and conceals their qualities that are similar to those of other people.

### **1.8.3 Family caregivers**

A family caregiver can be defined as a family member who, without financial compensation, regularly assists a person in carrying out one or more instrumental activities of daily living (Collins et al., 2011:1309; Shewchuk and Elliott, 2012:555). Most studies assume parents (especially mothers) are the primary caregivers of persons with disabilities and therefore previous research findings might refer to parents only.

For this study, however, the term ‘family caregiver’ referred to any adult family member (whether parent or other family member) that takes care of the person with the physical disability. Participants must be taking caring care of a person with an acquired or congenital disability that excludes disability due to aging. The reason for this is that it is possible that family members might encounter situations where young adults are suddenly faced with a disability due to car accidents, gang violence, or

suchlike. It is also possible that family caregivers had to take care of the child, who grows up to be an adult, for the rest of their lives.

#### **1.8.4 Ecological perspective**

The ecological perspective developed from Bronfenbrenner's model of community levels according to which there are a series of nested systems, fitted into one another. The four levels that Bronfenbrenner identified were the micro-, meso-, exo- and macrosystem (Visser, 2007:25). This perspective is discussed further in Chapter Three.

### **1.9 RESEARCH AREA**

The research study took place in various suburbs of Cape Town in the Western Cape province of South Africa, under the auspices of the Tygerberg APD.

### **1.10 ETHICAL CONSIDERATIONS**

For this research study to be performed, some ethical considerations were taken into account. These included ethical clearance and ethical issues.

#### **1.10.1 Ethical clearance**

A proposal of the intended research project was submitted to the Research Ethics Committee (REC) of the University of Stellenbosch. This ethical committee assessed the proposed study and provided ethical clearance before the empirical study was done. Proof of this ethical clearance can be found in Annexure A.

#### **1.10.2 Ethical issues**

Some of the ethical issues that are important to consider throughout qualitative research include avoidance of harm, voluntary participation, informed consent, confidentiality, compensation, debriefing of participants and publication of findings.

##### **1.10.2.1 Avoidance of harm**

As mentioned before, the study made use of semi-structured interviews. Drisko (2013:35) points out that narrative inquiry could generate very personal information that often would only be disclosed to therapists. Qualitative researchers often need to access very intimate details of participants' lives, which might have them feel exposed. As the study is categorised as a medium-risk study under the REC

submission, it is important that the researcher was aware of participants' possible feelings and approached the interviews with the notion of not doing any harm to the participants. An empathetic, non-invasive approach was followed during the interviews that were conducted.

#### 1.10.2.2 Voluntary participation

Rubin and Babbie (2005:71) stress the fact that participation in a research study should always be voluntary and that no one should be forced to participate. Social workers may not use coercion to convince people to participate (Drisko, 2013:30-31). Participants in this research study were informed beforehand that they had a choice in participating or refusing to participate in the study.

#### 1.10.2.3 Informed consent

Social workers must obtain participants' consent for specific procedures or actions and not only use broad and vague descriptions. Clear and understandable terminology must be used whilst respecting participants' right to refuse or withdraw consent (Drisko, 2013:30-31).

The researcher provided an information sheet about the study to the organisation in both English and Afrikaans (see Annexure G). This information sheet was then handed to possible participants, where necessary. The information sheet contained the content and purpose of the study as well as the contact details of the researcher. The organisation identified certain participants prior to the researcher contacting them to set up an interview date. All the participants for this study signed an informed consent form. The consent form was available in both Afrikaans and English to ensure that participants could understand the content of the research study best in their home language. They signed two copies of the Consent to Participate form (one of which they kept for themselves) when they agreed to be part of the study. A copy of this form can be found in Annexures C and D in both English and Afrikaans respectively.

Interviews only commenced after informed consent forms were read, understood and signed by the participants.

#### 1.10.2.4 Confidentiality

Confidentiality is one of the core values of social work (Drisko, 2013:34). Giving participants the reassurance that their information would be kept confidential means that the information shared with researchers will not be disclosed in any way that could publicly identify a participant. Participants were informed that identifying information would be stored in a secure location separate from the data that would be used for analysis. Since interviews were audio taped, names of participants were, as far as possible, not mentioned during the interviews. With the transcription of the interviews, names of the participants were not given; only pseudonyms were used (Given and Munhall, 2008:112).

For this study, minimal identifying particulars were present. The interviews that were recorded will be kept in a safe with a security code and all transcribed material will be kept on an encrypted file. No direct data will be shared by anyone other than the researcher and her supervisor. The following research-related records will also be kept in a safe and secure place: the REC-approved research proposal and all amendments, all informed consent documents, recruiting materials, continuing review reports, notes on adverse or unanticipated events, and all correspondence from the REC.

#### 1.10.2.5 Compensation

To ensure the legitimacy and efficacy of the research study, no participant was compensated for being part of the study. However, provision was made for participants not to have any transport costs, as interviews were conducted in their area, mostly in their own homes. The key issue with regard to compensating participants is that it might affect the outcome of a study. Participants may only participate to get the compensation and not because they really want to enhance the outcome of the study (De Vos et al., 2011:122).

#### 1.10.2.6 Debriefing of participants

‘Debriefing of participants’ refers to sessions during which participants get the opportunity, after the study, to work through their experiences. It is also an

opportunity where they can have their questions answered and misconceptions removed (McBurney, 2001:60). All the participants of this study were given the option to be referred for debriefing with Mrs Celista Gerber, a social worker from the Tygerberg APD. Some of the participants specifically asked for further service delivery and referrals were made to the Tygerberg APD.

#### 1.10.2.7 Publication of findings

The research study will only be published for academic or professional purposes. Participants' identities will not be disclosed in these publications. Should findings be published it would be done according to the REC guidelines.

### 1.11 LIMITATIONS OF THE PRESENT STUDY

There were some limitations to the study that should be identified, namely:

- The paucity of literature on the topic makes it difficult to relate to previous research and compare findings, however it could hold potential for future similar studies (discussed in Chapter Five).
- South Africa does not have a fixed measuring tool for disability, which means statistics on disability prevalence cannot be compared with one another due to different criteria used.
- This study was done with only 20 participants from a specific community within the Western Cape (only one of the nine provinces of South Africa). This means that the sample was a very small representation of the research universe and assumptions that the findings of the study could be generalised to all family caregivers of persons with physical disabilities cannot be made. Further, more in-depth studies, with bigger samples, would have to be conducted to confirm that the outcome of this study is the same for all family caregivers of persons with physical disabilities.
- Although the wide spectrum of identifying particulars of the participants gave a comprehensive view of the different experiences of family caregivers, it was also a limitation to the study as it prevented the focus on one specific group of participants, for example parents of children with a congenital physical disability.

- Similarly, the study was further limited in its ability to draw a true comparison between the different participants' needs, for example sibling caregivers versus parental caregivers.
- The study provided an overview of many themes and participant groups, which holds potential for future studies, but also limits the extent in which this research study could focus on these aspects without overcomplicating the study.
- A pilot study was intended to take place but due to the lack of participants it could not be done.
- The homes of some of the participants where the interviews were held were small, which meant that it was not always possible to ensure the necessary privacy for the interviews. This means that participants might not have shared as much as they would have liked to.
- Some participants were not very comfortable in talking freely during interviews, which meant that the researcher frequently had to guide them in terms of answers, which is not the ideal and could inhibit the authenticity of their answers. If a pilot study were done, this challenge could possibly have been picked up and the interview schedules could have been simplified to ensure more comprehensive answers.
- Since the participants did not always give comprehensive answers, the research study had to make use of denaturalised transcripts.
- Some of the resources were dated due to a lack of recent relevant research. The researcher attempted to balance it out with more recent journal articles.

## **1.12 PRESENTATION**

This research study is presented by way of five chapters as well as eleven annexures. Chapter One is the introduction to the research study. Chapter Two discusses the previous research on support needs of family caregivers of persons with congenital and acquired physical disabilities. Chapter Three utilises the ecological perspective to explore the different resources that support the needs of family caregivers of persons with physical disabilities. An analysis of the family caregivers of persons with physical



disabilities' perceptions of their support needs being met is done in Chapter Four whilst Chapter Five is the relevant conclusion and recommendations for future study.

Some annexures are added to the thesis. These are the REC approval notice, the consent form for research through the Tygerberg APD, consent forms for participants (English and Afrikaans), examples of questionnaires (English and Afrikaans), the research information sheet (English and Afrikaans), the member checking verification (English and Afrikaans) and the independent coder theme verification.

## **CHAPTER TWO**

### **THE NATURE AND SCOPE OF FAMILY CAREGIVERS WHEN CARING FOR A PERSON WITH A PHYSICAL DISABILITY**

#### **2.1 INTRODUCTION**

In this chapter, the nature and scope of family caregivers caring for a person with a physical disability is discussed. This chapter, which reflects the first objective of the study, first focuses on the description of disability, and the onsets and prevalence of disability. Next, caring for a person with a physical disability is discussed in terms of the role of the family caregiver, the positive and negative experiences of family caregivers in their caregiving role, the barriers they experience, and the coping mechanisms they use to overcome these barriers.

#### **2.2 OVERVIEW OF CARING FOR A PERSON WITH A PHYSICAL DISABILITY**

Living with a person with a disability can have significant effects on the entire family, including parents, siblings as well as the extended family members. This unique shared experience can affect all aspects of family functioning in both a positive and a negative manner (Reichman, Corman and Noonan, 2008:679).

On the positive side, it can broaden horizons, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the above-mentioned authors claim that raising a person with a disability can have wide-spread effects due to the time and financial costs, physical and emotional demands, and logistical obstacles faced. The exact impact will depend on the type of disability and the severity thereof. Reichman et al. (2008:679) also emphasise the need to study how children's health, especially in terms of disability, affects their parents, siblings, grandparents, and extended family members.

Caregivers of persons with disabilities can be categorised into formal caregivers, informal caregivers or family caregivers. Formal caregivers are volunteers or paid employees usually working within the social service or health-care systems, in services provided by professionals such as school programmes, parent education specialists,

therapists and respite-care agencies. Informal caregivers are family members and friends who act as the primary source of care. The family caregiver refers to a close relative that provides care. Caregivers assist or provide care for people who need help in activities of daily living such as bathing, dressing, preparing meals, transfers, ambulation and shopping. Some might also have added responsibilities of administering medication and managing household finances (Dawson, Balloch and Moore, 2011:109,115). While caregiver stress has been studied in many developed countries, few formal studies have been conducted in developing countries such as South Africa (Gupta, Mehrotra and Mehrotra, 2012:43). The findings of some previous studies are noteworthy, but as mentioned earlier, there have not been many studies with the same focus as this one and this study was reliant on the findings of similar studies.

Andrén and Grimby (2004:528) conducted a follow-up study (five years after their first study) on adults with spina bifida (SB) and cerebral palsy (CP) in Sweden and noted that most previous research on persons with CP and SB, their degree of dependence and needs and services, have focused on children or adolescents. They found in their study that 16% of the young adults were living with their parents at the first assessment but at the second assessment this had decreased to only 10%. At the first assessment, 71% of the participants were fully or partly employed and one subject was studying. At the second assessment, this total increased to 81% that were employed, none were studying and two participants were receiving a disability pension.

In Broodryk's (2014) study on the caregivers of persons with a brain injury, it was found that family caregivers play a significant role in the lives of those that they care for and may face many challenges as a result of their caregiving role. These challenges could have an impact on their physical, psychological and social well-being.

Due to the lack of research, the researcher in the current study was reliant on the information of similar studies with minor differences in variables (e.g. other age groups but same disability, or same age group but different disabilities) which is used as a precedent for this study. The differences and similarities to these studies are discussed in Chapter Four (see section 4.4.).

## **2.3 SCALE OF DISABILITIES**

According to the International Classification of Functioning, Disability and Health (ICF) there are three dimensions of disability, namely impairments, activity limitations and participation restrictions. Impairments refer to problems in body function or structure. Activity limitation refers to difficulties a person may have in executing tasks or actions. Both of these could then influence the participation restrictions, which refer to the person not being able to experience full involvement in life situations (compared to a person without a disability). How the person experiences these limitations can be affected by contextual factors such as social attitudes, legal and social structures and internal personal factors (DWCPD and UNICEF, 2012:22). There are various forms of disabilities. In this study, the focus was on physical disability, although there are other types of disabilities, as mentioned in Chapter One.

### **2.3.1 The meaning of ‘physical disability’**

In this study, the term ‘physical disability’ includes all forms of disabilities that can have an impact on a person’s physical capabilities. Some of the disabilities that could, be included in this group but are not limited to it, are: spinal cord injuries, visual impairments, hearing impairments, cerebral palsy and muscular dystrophy. Physical disability includes anatomical loss or musculoskeletal, neurological, respiratory or cardiovascular impairment. Physical disabilities can be either congenital or acquired after birth, as will be discussed later (PACER, 2004:1).

### **2.3.2 Different onsets of physical disability**

There are various reasons why a person may become disabled (Handicap International, 2009:1). The cause or onset of disabilities can be split into two main categories: congenital/hereditary or acquired/environmental.

A congenital disability is present from birth as a result of either heredity (e.g. SB and CP) or environmental influences (Careerforce, 2015:9; PACER, 2004:1). Congenital diseases are a significant cause of disability, especially in developing countries (Nacul, Moorthie, Kapila & Zimmern, 2010). During this study, congenital disabilities would

include any physical disability (see explanation of physical disabilities) that has been present since birth, for example SB, CP and muscular dystrophies.

An acquired disability is a disability that occurs after birth and can be caused by an accident or disease (PACER, 2004:1). People acquire physical disabilities through aging and various forms of accidents, diseases and infections (trauma) (Careerforce, 2015:9; Elliott, Kurylo and Rivera, 2002:687). In this thesis, ‘acquired disability’ refers to any physical disability that a person has acquired after birth, for example. spinal cord injury.

Bogart (2014:6) emphasises that there is a crucial difference between congenital and acquired disability, especially in terms of the way people incorporate their disability into their self-concept. The research study explored the experiences of family caregivers of persons with congenital as well as acquired physical disabilities.

### **2.3.3 Prevalence of different disabilities**

The prevalence of disability is an important matter for consideration since – as stated before – many persons with disabilities would rely on families to take care of them. The prevalence of disability could then be a preparatory indication of how many families would need assistance. It was therefore important to look at the prevalence of specifically physical disabilities around the world, as well as in South Africa and particularly the Western Cape.

#### **2.3.3.1 Prevalence of disability worldwide**

The WHO estimated in 2011 that around 10% of the world’s population (around 700 million people) were living with a form of disability. Disability does not only affect the person self but also has an impact on their support network, that is, friends and family (Hartley et al., 2011:139).

#### **2.3.3.2 Prevalence of disability nationwide (South Africa)**

Koopman (2003:3) refers to the 1996 Census of South Africa estimating the percentage of people with disabilities as 6.6% of the population. According to the researcher, this percentage was similar to the special survey conducted by the

Department of Health (DoH) and the Community Agency for Social Enquiry in 2003 that estimated the percentage of persons with disabilities in South Africa at 5.9% of the population.

In Census 2001 (Statistics South Africa, 2005:11), it was found that physical, hearing and sight disability prevalence added up to 65% of the total disability prevalence rate in South Africa – far more than emotional or intellectual disability. Redfern (2013:21) support this by referring to the results from the South African Census 2001 (Statistics South Africa, 2005:13) indicating that the different sub-categorised percentages of persons with disabilities were as follows: visual disability (32%), physical disability (30%) and hearing (20%). These add up to 82% of the total population with disabilities. The Census of 2001 in South Africa reported that 436 123 children (2.5% of the child population) had some form of serious disability and about 2 255 982 of the total population in South Africa had a disability.

In 2003, a District Health Survey was also conducted by the DoH and the Medical Research Council which reported that the overall disability prevalence for the population aged up to 19 years old was 5.3%, specifying visual as 1%, hearing as 0.3%, speech as 0.1% and physical as 2.6% (Redfern, 2013:21).

Statistics South Africa (2005:13) indicated that in 2005, the total number of persons with a disability in South Africa in 2005 was 2 255 982 of which the different types of disabilities were estimated as 724 169 people with sight disabilities, 543 104 people with hearing disabilities, 146 164 people with communication disabilities and 668 082 people with physical disabilities.

According to the Census of 2011 (Statistics South Africa, 2014:8) there were 2 870 130 people with disabilities in South Africa. However, this number could be higher since only 38 million people were part of this Census although the population size was estimated to be 51 million people at the time. Redfern (2013:21) cited the General Household Survey from August 2012 (Statistics South Africa, 2013) that indicated that an overall prevalence of disability in the population was estimated to be 5.1%, with the majority of this being amongst adults. Redfern commented that this figure

was likely to under-represent childhood disability for various possible reasons such as the fact that the under-five age group was excluded from the census and that there is stigma attached to having a child with a disability.

#### 2.3.3.3 Prevalence of disability in the Western Cape

According to the Census of 2001 (Statistics South Africa, 2005:11-13), about 186 850 people with disabilities live in the Western Cape. Of these disabilities, physical, hearing and sight disability added up to 49% in 2001. The Census of 2011 (Statistics South Africa, 2014:8) revealed that there were 222 333 people with disabilities in the Western Cape. It was further estimated that the prevalence of children with disability or a disabling chronic illness in the Western sub-district was 1% of the child population. Based on the number of care dependency grants ( $n = 1748$ ), the study estimated that the prevalence of children with disability in the Western sub-district was 1.6%. These children often grow up to be adults with disability (Redfern, 2013:21).

The statistics above indicate that about 0.4% of the world's estimated persons with disability are estimated to be living in South Africa. Of these, 7.7% live in the Western Cape.

## 2.4 CARING FOR A PERSON WITH A PHYSICAL DISABILITY

The most auspicious moment for parents is when they are blessed with a child. Parents usually have high aspirations and dreams for their children. When they then discover some anomalies with their child at birth, this vision may be suppressed and different emotions may be experienced (Gull and Nizami, 2015:144). Feelings of guilt may arise as one or both parents may feel that they caused the child's disability through genetics, alcohol misuse or stress (Trollope, 2013:9).

When a child acquires a disability later in life, the adjustment that both the person (the child) and his/her family must make causes certain emotions and experiences. Again, feelings of guilt may arise where one or both parents may feel as though they caused the child's disability for various reasons (Trollope, 2013:9).

Kendall and Buys (1998:16) suggest that the adjustment that must be made after an acquired disability is best described as a recurrent process, often characterised by continuous sorrow. The sorrow is likely to re-emerge regularly in a repetitive pattern of despair and acceptance. Their study also found that following a permanent disability, individuals alternated between 'pre-disability' identity and their new 'disability' identity. Although their findings were related to the person with the disability, this response predicts possible outcomes for this current study that focuses on family caregivers of persons with physical disabilities and how they experience the adjustment.

Family members may shift in their own adjustments and abilities to cope with the caregiving demands, thereby affecting the person with a physical disability's ability to cope. In some situations, family members will adjust by making a conscious choice between the goals of the person with a disability and those of the health-care professional, which may be contradictory. In other cases, family members may be unable to adjust to the changes imposed by the disability and display more distress than the person with the disability. Family members in caregiving roles can have an impact on the psychological and physical adjustments of persons with disabilities (Migerode, Maes, Buysse and Brondeel, 2012:487).

An acquired disability, however, does not always lead to negative experiences only. It can force family members to confront issues of trust, mortality and values, which would require them to develop deeper commitments and even redefine the meaning of marriage or kinship. Some family members have reported a greater sense of intimacy, greater family and personal relationships and positive changes in shared family values (Elliott et al., 2002:687).

In general, it seems that although adjustments must be made by the person with the disability and their family in both congenital and acquired disabilities, there is a difference in experiences between these disabilities. If a child was born with a congenital disability, it might start out as a disappointment for the family and it might mean that they must commit to life-long care for the child. However, they become accustomed to this lifestyle and start to adjust to it. When a person acquires a disability later in life then



both such a person and his/her family should not only adjust to the disability itself, but also refrain from continuously comparing their ‘pre-disability’ lifestyle to the ‘disability’ lifestyle.

#### **2.4.1 Role of family caregivers in caring for persons with physical disabilities**

For almost all parents, caring for a child is an experience filled with triumphs and joy as well as challenges and stress. The parenting responsibilities for parents of children with disabilities often require a great deal of time, can be physically demanding, and can disrupt family and social relationships. Such responsibilities can also negatively affect caregiver employment (Resch, Mireles, Benz, Grenwelge, Peterson and Zhang, 2010:139). All these aspects are discussed later in this chapter.

Simplican, Leader, Kosciulek and Leahy (2015:27) found that most people with intellectual and developmental disabilities, which could include physical disabilities, live with their families. As informal caregivers, family caregivers provide long-term care which often requires exceptional physical, emotional, social and financial resources. Not only are they usually responsible for the physical care of their child, they must also coordinate their child’s numerous and multifaceted medical, education and developmental interventions while still balancing family needs of other family members (Murphy, Christian, Caplin & Young, 2007:184). Examples of these interventions or support include the following: helping their dependent family members with daily tasks, making appointments, managing finances and medication, organising socialisation and recreational activities, and supervising and assisting their family member with bathing, meal preparation, and feeding (Broodryk, 2014:6-7).

Parents (or other family caregivers) play an important role in providing social and emotional support for children and adolescents, especially for children with a physical disability. This is due to the shift of rehabilitation services from being institutionalised to being provided at home. The role of parental support is very complex and has produced varying results in research. Some studies suggest that persons with physical disabilities experience a sense of overprotection by their parents whilst others report

the relationship with parents as being supportive and important to their success (Antle, Mills, Steele, Kalnins and Rossen, 2008:191).

Children with disabilities depend greatly on the willingness and ability of their parents to adopt unexpected 'informal caregiving careers', roles that typically span the course of a child's life (including adulthood). Parents tend to worry about the importance of daily routines that will promote their child's well-being (Antle et al., 2008:191). Moreover, they must balance these needs of the child with the general needs of other family members (Murphy et al., 2007:184).

Cohen and Napolitano (2007:149) claim that a family's response to disability has a powerful influence on the individual. They refer to the actor, Christopher Reeve, who was thrown from a horse, after which he was paralysed. He noted the importance of family support during his rehabilitation.

A study by Antle et al. (2008:191) found that besides providing normal daily support, parents also make a great effort to help facilitate the participation of their adolescent with a physical disability in developing friendships.

## **2.5 EXPERIENCES OF FAMILY CAREGIVERS WHEN ADAPTING TO CARE FOR PERSONS WITH PHYSICAL DISABILITIES**

As noted before, most parents eagerly anticipate the birth of a healthy child. Because of this expectation, the initial diagnosis of disability is seen as the shattering of that ideal. Parents and other family members may experience different feelings once confronted with the significant change caused by someone close to them having a disability.

Due to the lack of previous research relating to family caregivers of persons with physical disabilities, the coping strategies of family caregivers of various disabilities have been used as a precedent study for this study. As mentioned before, the child with a physical disability will usually remain with his/her parents as an adult as well. This will be discussed further in this chapter.

Family caregivers operate as extensions of health-care systems (performing complex medical and therapeutic tasks as well as ensuring adherence to therapeutic programmes).

However, they usually do not receive adequate training, preparation, or ongoing support from these systems. The responsibilities of caregiving, as well as the lack of preparation, guidance and support erode their physical and emotional health and their financial resources (Elliott and Pezent, 2008:2).

### **2.5.1 Feelings related to grief**

A person's disability is a triadic experience, involving the person who experiences the disability, the family that is affected by it, and the external environment where the disability is manifested. In most cases, families' initial reactions are likely to be negative, and similar to those related to grief.

Ross and Deverell (2010:36) define grief as the process whereby a person can separate themselves from someone or something that has been lost. They adapted the five stages of grief identified by Kübler-Ross (1972) into nine phases, as discussed in the subsections below. According to them there are nine phases of grief, namely shock/disbelief, relief, denial, bargaining, guilt, depression, anger, anxiety and acceptance. In their research, Ross and Deverell (2010) focused specifically on the scenario where the child was born with a disability but their study could also be relevant in the case where the family member acquires a disability later in life.

#### *Phase One: Shock, numbness and disbelief*

One of the first reactions is a feeling of shock, numbness and disbelief due to the unexpected diagnosis of the disability. Finding out one's child has a disability could make parents feel that their hopes and dreams for their child are shattered and they might start worrying about what the diagnosis entails (Ross and Deverell, 2010:36).

#### *Phase Two: Relief*

In cases where family members may have suspected that something was wrong but could not get a formal diagnosis, once the diagnosis is clear, they may feel relief either for finally knowing or for finding out the disability is not as severe as expected, for instance, suspecting the child is completely deaf and finding out he/she is merely hearing impaired on one side (Ross and Deverell, 2010:36).

*Phase Three: Denial*

Denial is also one of the first responses to finding out one's child has a disability. Parents can display denial in various ways, for instance they might reject the diagnosis and argue with the health professional or they may completely ignore the diagnosis and prescribed treatment (Ross and Deverell, 2010:37).

*Phase Four: Bargaining*

The bargaining phase is characterised by fantasy thinking. Upon diagnosis, family members may try to bargain with themselves, God or their therapists, making idealistic promises for a complete or significant improvement in the child's problems (Ross and Deverell, 2010:37).

*Phase Five: Guilt*

Many parents or family members of disabled children may feel guilty about the cause of the disability and may feel it is their fault that the child has a disability. Guilt can be displayed in three ways, namely through stories of what they believe caused the disability, their belief that the disability is a punishment to them and through the 'just world' hypothesis – "Good things happen to good people and bad things happen to bad people" (Ross and Deverell, 2010:37).

*Phase Six: Depression*

Reactive depression usually occurs during the grieving process which is different from the endogenous depression caused by chemical imbalance. Family members may feel helpless and powerless which leads to them feeling 'an anger turned inward'. Depression is a normal and necessary part of the grieving process as it long as it does not continue for too long (Ross and Deverell, 2010:37).

*Phase Seven: Anger*

Anger can reveal itself in various ways during the grieving process, for instance anger about why it happened or anger towards other parents with non-disabled children (Ross and Deverell, 2010:37).

*Phase Eight: Anxiety*

Family caregivers may have general feelings of panic and anxiety. The anxiety is usually related to the question of how to balance the extra responsibility for the welfare of the person with the disability versus having an independent life of one's own (Ross and Deverell, 2010:37).

*Phase Nine: Acceptance*

Acceptance is achieved when parents reveal some of the following characteristics:

- Ability to discuss the child's limitations without feeling vulnerable
  - Demonstrating a balance between encouraging independence and showing love
  - Ability to work with professionals to formulate short- and long-term plans
  - Pursuing personal interests that are not related to the child with the disability
  - Ability to exercise appropriate discipline without experiencing excessive guilt
  - Refraining from being overprotective or excessively harsh towards their child
- (Ross and Deverell, 2010:38).

This final phase that coincides with Kübler-Ross's (1972) final stage of grief can also be seen as a positive aspect or experience in caring for a family member with a disability.

## **2.5.2 Negative experiences**

Informal care is usually seen as an efficient and cost-effective way of caring for people with disabilities. However, as stated before, exclusive reliance on informal support can have significant consequences for caregivers, including compromised health-related quality of life such as posttraumatic stress disorder, emotional distress, caregiver burden, depression, and anxiety (Elliott and Pezent, 2008:2; Kress and Herridge, 2012:341). 'Caregiver burden' is an umbrella term that is used to describe the physical, emotional and financial responses of a caregiver to the changes and demands of providing help to another person with a disability (Jeong et al., 2015:619).

Caregivers have a parallel but different experience compared to the person with the disability they are taking care of. They have various responsibilities and roles in helping the person with the disability integrate, as best possible, with society. These family

caregivers often do not have a voice and suffer in silence, which has a significant impact on their family member with the disability for whom they are caring (Kress and Herridge, 2012:341).

Reichman et al. (2008:680) conducted a study that focused on the impact of child disability in general on the family. Although the type and the severity of the disability would have a specific impact on the family, the researchers note some general experiences that have been found to be true in most cases where there is a child with a disability. It was therefore relevant to take these effects into consideration in this current study as well. According to Reichman et al. (2008), some of the impacts of having a disabled child in the family are the financial, emotional and effects on family. Regarding the financial aspect, families may experience difficulty in finding appropriate and affordable child care, out-of-pocket costs of medical care and other services may be substantial, and they might have to rely on public support. On the emotional front, families may experience guilt, blame, or reduced self-esteem. Lastly, within the family context, there might be a change in parents' allocated time and financial resources for their non-disabled children as well as certain expectations of non-disabled siblings in terms of achievement and responsibility.

Research conducted by Trollope (2013:9) focused on raising a child with a mental disability. In this study, it was found that parents may struggle with feelings of guilt. One or both parents may feel as though they caused the child's disability either through genetics, alcohol misuse, stress, accidents or other logical or illogical reasons. Such feelings of guilt can harm the parents' emotional health if they are not dealt with. Furthermore, some parents may also struggle to find the reasons for the disability ('why?') and experience a spiritual crisis or even blame the other parent. Lastly, parents may also experience severe disappointment in view of aspirations they might have had for their child.

Reichman et al. (2008:680) suggest that having a disabled child and having to provide lifelong care may increase stress and take a toll on the mental and physical health of parents. Other emotions families may experience include ambivalence, anger, denial,

depression, embarrassment, fear of stigma, grief, shock and even withdrawal. These feelings can be caused by the sudden recognition that the anticipated 'normal child' they had waited for nine months is not a reality. Due to their child's disability, parents may suffer an unending sense of loss. However, some parents show greater tolerance for these stressors than others (Gull and Nizami, 2015:144). Many caregivers occasionally experience burn-out, which has been described as overwhelming feelings of despair with no end in sight (Murphy et al., 2007:184). The parents must be helped to establish realistic objectives at their children's level of abilities. They also need guidance on how to encourage the self-awareness and self-esteem of their children from an early age (Arellano and Peralta, 2013:179). Antle et al. (2008:191) found that parents had recognised their child with physical disability was different which led to worries for their future, for instance regarding opportunities of education, employment, financial independency and the ability to live on their own.

Caregivers who experience problems with depression and burden may be more likely to institutionalise dependent family members. Depressed caregivers may display potentially harmful and abusive behaviours toward care recipients (Elliott and Pezent, 2008:2). Caregivers perceive in-home support services negatively because of feelings of inadequacy and loss of environmental control. Caregivers with compromised health, such as their own physical or psychological limitations, may find it more difficult to complete caregiving tasks. Caregiving is also associated with physical, psychological and financial burdens for caregivers (Collins et al., 2011:1309-1317). Family members often experience depressive symptomatology in caring for stroke survivors (who may have physical disability due to stroke), with rates ranging from 34% to 52% or even higher in the first three months after return to the community (Grant, Elliott, Weaver, Glandon, Raper and Giger, 2006:343).

Some other consequences a caregiver may experience are stress, fewer opportunities for employment, financial issues, poor emotional health, greater difficulties as family members age, physical health issues, school-related issues, and other barriers (Hartley et al., 2011:142). There is also evidence to show that most caregivers are ill-prepared for their role, and provide care with little or no support (Dawson et al., 2011:115).

### 2.5.2.1 Stress

The demands of caring for a person with a disability often result in stress for families, particularly for women, who tend to be responsible for domestic chores, which would then have to be balanced with caretaking (Hartley et al., 2011:142). Modifying factors of caregiver stress include the characteristics of the caregiver (e.g. age, marital status, coping ability), characteristics of the recipient (e.g. the degree of disability), the shared history (relationship) between the caregiver and the person being cared for, social factors (e.g. access to social networks and social support), economic factors (e.g. socio-economic status, ability to access formal care, employment), and cultural context (Parminder, O'Donnell, Rosenbaum, Brehaut, Bin and Wood, 2005:627).

These factors suggest that stress occurs in a broader context than merely just caring for a child with a physical disability (Parminder et al., 2005:627). Primary caregivers – usually the parents – are under continuous stress to maintain their child's health and well-being. These stressors may contribute to this increased risk, including feelings of uncertainty over child health outcomes, daily difficulties associated with medical regimens, social isolation, role restrictions, and financial strains (Shanbhag and Krishanmurthy, 2012:36).

Murphy et al. (2007:184) found that many caregivers felt they lacked control of their daily activities. Caregivers reported that they felt they had too little time to complete daily tasks and were worried that they were not meeting the needs of other family members. Caregivers also described the need to repeatedly advocate for their child with a disability as another major source of stress.

### 2.5.3 Positive experiences

Positive aspects of caregiving, on the other hand, reduce the negative effects of caregiving and decrease the burden. Some caregivers reported that caregiving made them feel useful, needed, important, and confident. They reported lower levels of burden, demonstrating the potential positive effect of a caregiver's psychological approach (Rodakowski, Skidmore, Rogers and Schulz, 2012:2229).



## **2.6 BARRIERS EXPERIENCED BY FAMILY CAREGIVERS OF PERSONS WITH PHYSICAL DISABILITIES IN ACCESSING RESOURCES**

Parents of persons with disabilities identified several barriers to accessing resources, according to the findings of Murphy et al. (2007:184). These barriers were a lack of time, a lack of respite hours, a lack of qualified alternative care providers, and low prioritisation of their needs.

Societal attitudes have been identified as barriers to employment opportunities. Infrastructural elements have also been found to act as barriers to health maintenance, for example inaccessible medical facilities and equipment and the lack of accessible exercise and recreation facilities (Nosek, Hughes, Howland, Young, Mullen and Shelton, 2004:6-21).

### **2.6.1 Health-care issues**

Hartley et al. (2011:64) discussed the reasons why people have a lack of health care. These reasons were found to be inadequate finances, transport, health-care provider skills and equipment, treatment, time off work and knowledge regarding the situation or where the facility is.

#### **2.6.1.1 Health-care financing**

Hartley et al. (2011:64) looked at reasons why people had difficulties in accessing health-care financing, for example difficulties in completing insurance application, finding out insurance benefits/entitlements and being reimbursed from health insurance. This current research study assessed whether these difficulties are also present in family caregivers of persons with physical disabilities in accordance to the Parents' Supportive Care Needs Framework discussed in Chapter Three.

### **2.6.2 Education issues**

Children with disabilities are often referred from special schools to non-governmental organisations (NGOs) and the DoH for assessment. The lack of adequate skills and facilities for assessment contributes to many challenges: long delays in placement while the child is waiting for an assessment; children not being assessed and therefore unable to access the required service; educators not knowing the extent of a child's

impairment and therefore not assisting the child appropriately; children developing secondary disabilities; and many disabled children only starting school long after the age of seven years which then also raises challenges for educators (DWCPD and UNICEF, 2012:60).

Mainstream public schools generally do not have the necessary resources to deal with the diverse needs of children with different health conditions and impairments. Since 2009, the Department of Basic Education (DBE) has introduced a programme of ordering Braille textbooks and workbooks for all schools that cater for persons with visual impairment, including those in mainstream public schools. Unfortunately, the lack of capacity in the country to produce Braille has made the process very slow and complex (DWCPD and UNICEF, 2012:59). By 2011, 28 000 teachers had been trained, but it was found that there was still a lack of skills in the area of curriculum differentiation, which challenged the implementation of inclusive education (DWCPD and UNICEF, 2012:60). Although there is evidence of an increase in awareness in the White Paper 6 on Education, some challenges still exist, especially with regard to the accessibility of educational institutions. Legislation and policies require buildings and facilities but many of them are not designed to provide full access to students with physical disabilities (Greyling, 2008:33).

In her research, Trollope (2013:9) states that the parents of a child with developmental disabilities may face complex school-related issues such as the need for information, advice, support and practical help and the need to be involved at every stage in the identification and assessment of their child's education needs. Unfortunately, many parents' needs remain unmet (Russell, 2003:144). This is further discussed in Chapters Three and Four.

Statistics South Africa (2014) investigated the education level of persons with disabilities over 20 years and found that 22.6% of persons with visual impairments, 29.1% of persons with hearing impairments and 29.8% of persons with physical disabilities have no schooling. From the rest of the population group only 24.4% of persons with physical disabilities, 24.8% of persons with hearing impairments and

27.9% of persons with visual impairments completed high school. Only about 4% to 5% of each of these groups went on to finish higher education.

### **2.6.3 Employment issues**

There are two main issues related to caring for a person with a physical disability that have family caregivers, that is, employment for themselves and employment for the PwD.

#### **2.6.3.1 Employment for persons with physical disabilities**

In the Western Cape, the employment rate of persons aged 15 to 64 years was highest for persons with visual impairments (41.9%) whereas for those with hearing impairments it was 35.8% and for those with physical disabilities only 21.6% (Statistics South Africa, 2014).

#### **2.6.3.2 Fewer opportunities for employment and financial issues for caregiver**

Due to the time-consuming responsibility of taking care of a family member with a disability, a loss of economic opportunities may be experienced, as caregivers would either have to reduce their paid work or refrain from it completely. This may then lead to financial issues (Hartley et al., 2011:142).

Many caregivers adjust their work schedules, take periodic leave of absence or reduce work hours to fulfil their caregiving responsibilities. Additional costs stemming from this state of affairs include loss of salary and benefits, loss of promotional and training opportunities and a reduction in retirement savings (Collins et al., 2011:1309-1317).

Not only do family caregivers experience trouble with employment, they also have other financial issues that are exacerbated by the lack of employment. Trollope (2013:9) refers to the World Health Survey data analysis of 15 developing countries that indicated that households with disabled members tend to spend more on health care than those without disabled members. The additional spending on health-care services may include assistive devices, special diets or personal care and assistance. Other additional spending could include specialised transportation, heating, laundry services and assistance (Hartley et al., 2011:41).

The care of the child with the disability may also last a lifetime instead of the general 18 years. Parents may have to set aside money in a trust fund to ensure the child's care when they pass away (Trollope, 2013:9). As mentioned before, financial difficulties may be exacerbated since parents of a child with a disability are more likely to have unstable or no employment, compared to parents without a child with a disability. It was found that after the birth of a child with a disability, 67% of mothers were unable to enter or maintain paid employment. Overall, families of children with disabilities experience decreased financial resources whilst facing increased financial demands (Wei and Yu, 2012:100).

Poverty and disability seem to reinforce each other, trapping people with disabilities and their families in a vicious cycle that puts them at a worsening disadvantage (Handicap International, 2009:1). Parents with a low income might not be able to provide for all the financial care that a child with a physical disability may need. They might not be able to pay for private (special) education, they will need to make use of public medical facilities and public transport, and they will most probably not be able to put money away in a trust fund for the child (Trollope, 2013:9).

For some families, the emotional and financial strain of caring for a child with a disability may irreparably damage the relationship between parents (Wei and Yu, 2012:100). The indirect costs of caregiving include loss of employment, lost career development opportunities and loss of time with spouses, family and self-care activities, but these are difficult to quantify (Murphy et al., 2007:184).

#### **2.6.4 Establishment and implementation of policies and legislation**

Although there are numerous policies in place within the disability sector, there are still some gaps, including the lack of a national policy on disability prevention. A 10-year review of the impact of government policies on persons with disabilities reported that the Department of Social Development identified a few key concerns regarding assessments for social security (grants) for adults and children with disabilities. These included lack of uniformity of assessment tools across provinces, lack of clarity regarding eligibility criteria for children, the subjective nature of assessment in

determining eligibility, the necessity for training of assessors, a lack of awareness regarding availability of grants particularly in rural areas, and corruption around grant administration and payment processes (DWCPD and UNICEF, 2012:73).

The following findings emerged from research on the effectiveness of disability policy implementation in South Africa (DWCPD and UNICEF, 2012:73):

- Policies are not aligned to programmes of action for implementation.
- Monitoring tools are lacking.
- There are insufficient personnel in departments with expertise and knowledge on disability issues.
- There is a lack of internal policies on disability.
- The definition of disability and the nature of disabled people's participation are inadequately articulated.
- Policy requirements for disability mainstreaming are not linked to performance management.
- There is a lack of budgetary allocations.
- Civil servants who have the responsibility for implementing disability policies are ignorant.
- Procedural bottlenecks are prevalent.

The DWCPD and UNICEF (2012:73) found that some provinces had developed integrated provincial disability strategies, but no budgetary allocations had been made and therefore there had been no significant implementation of these strategies in these provinces.

#### **2.6.5 Funding of non-governmental programmes**

According to the Children's Act 31 of 2005, Government is responsible for ensuring that comprehensive social services are provided for all children, with priority being given to the funding of services in poor communities. Although NGOs are rendering services mandated by this act, funds paid to them do not cover the full cost of providing these services. The Department of Social Development has acknowledged difficulties

with the funding of services provided by partner organisations (DWCPD and UNICEF, 2012:80).

NGOs working in the disability sector have expressed grave concerns regarding accessing government funding. Some organisations have reported that even where a service-level agreement is in place, funding does not always come through as agreed and that there is a general lack of understanding regarding the nature of services required for children with disabilities. The Department of Social Development, on the other hand, is concerned about NGOs' lack of administrative capacity, skills for financial management and writing of business plans (DWCPD and UNICEF, 2012:80).

#### **2.6.6 Social problems**

Certain social problems can act as barriers to persons with disabilities and their families. Problems such as attitudes, stereotypes, family roles, socio-economic conditions and communication barriers can all impair people's ability to participate in the community (Handicap International, 2009:1).

#### **2.6.7 Physical barriers**

Poor designing and planning creates barrier in the built environment, spaces and transportation, thus equal opportunities are denied to people with disabilities (Handicap International, 2009:1).

The impact of inadequate living conditions is particularly negative for children with disabilities. According to Statistics South Africa's Community Survey 2007, children with disabilities are less likely to have access to adequate housing, water and sanitation than their non-disabled peers. Children with disabilities are more likely to live in traditional dwellings and informal settlements than their non-disabled counterparts. Overcrowded living conditions and outside toilets place enormous stress on children with disabilities and their families (Rodakowski et al., 2012:2229).

#### **2.6.8 Respite services**

It was also found that this ongoing stress caused parents to wish for more respite or personal leisure time that did not require any caregiving to others. Some parents with

young children were reluctant to use respite care because they considered it their responsibility to look after their children themselves, and were reluctant to involve other people in caring for their children (Mannan, O'Brien, McConkey, Finlay, Lawlor and Harrington, 2011:43).

It was also common for caregivers to use respite hours to care for other family members rather than to restore themselves (Murphy et al., 2007:184). Parents who used respite care indicated that as time went by, the feeling of guilt decreased as the family gained from the breaks (Mannan et al., 2011:43).

### **2.6.9 Physical health issues**

Caregivers often place low priority on their own health compared to that of their children with disabilities and their other family members. Parents identified several barriers to promoting their own health; these included lack of time, a lack of respite hours, a lack of qualified alternative care providers for the child and low prioritisation of the need (Murphy et al., 2007:184).

Cantwell, Muldoon and Gallagher (2014:2220) point out that previous research linked the stress of caring for children with developmental disabilities with parental mental health outcomes. They contend that parents' physical health would also be influenced by factors such as poor sleep, greater risk of hypertension, arthritis, increased headaches and higher rates of infection.

Murphy et al. (2007:184) found that the caregivers who participated in their study tended to rank their own health needs as the lowest priority and indicated that most of their time and effort was invested in caring for other family members. Almost all their participants had experienced chronic fatigue and sleep deprivation. Most caregivers described one or more chronic physical ailments that they directly attributed to the long-term effects of caregiving. The negative physical consequences were the most evident among mothers, who were the primary caregivers in most families. In this study, parents reported suffering from shoulder pain, which they associated with the regular lifting of the child. More than 70% of mothers of children with physical disabilities reported low

back pain. Some caregivers had also been directly injured by their children's impulsive and occasionally violent behaviours.

In general, participants in the study of Murphy et al. (2007:184) felt that the caregiver's physical challenges were more demanding when their child was young but that their own health suffered more when the child got older. Approximately 60% of the caregivers reported difficulty in performing daily work because of their poor physical health whilst slightly more than 50% had experienced moderate to severe physical pain within the last four weeks. Several older caregivers reported that they had developed osteo-arthritis because of years of caregiving. The painful symptoms had persisted and led to their finally having to move their child from home to collective care centres.

Caregivers carry a great risk of becoming ill themselves. High rates of insomnia and depression, serious illness and lack of preventive health measures have been found in caregivers (Collins et al., 2011:1309).

#### 2.6.9.1 Greater difficulties as family member(s) age

A child that is born with a physical disability often requires care their whole life. Persons (young unmarried adults specifically) may acquire a disability later in life which might lead to their requiring care from family caregivers as well.

Family caregivers often assume the main, multi-faceted responsibilities of long-term disability management. Caregiving for a child takes on a more intense role when a child experiences functional limitations and possible long-term dependence (Parminder et al., 2005:627). As parents or other family members who contribute to care grow older and become frail or die, it can be difficult for the remaining family to continue providing care (Hartley et al., 2011:142). It is also important to consider that the person with the disability also gets bigger and older, which may make it more difficult to take care of them. Feeding, bathing, moving, clothing and diapering an infant is much easier physically than doing the same tasks for a fully grown adult (Trollope, 2013:9).



Older adults who act as caregivers may be vulnerable because caregiving may tax their health and physical abilities and compromise their immune response systems, and the caregiving stress can worsen existing chronic health conditions (Elliott and Pezent, 2008:2).

## **2.7 COPING MECHANISMS USED BY FAMILY CAREGIVERS FOR PERSONS WITH PHYSICAL DISABILITIES**

Although there are many challenges that caregivers of persons with physical disabilities face, some resources have been reported to help them cope in these struggles. Some such resources are support groups, respite care, psycho-education, social support, and close relationships. Of these, social support, specifically, has been identified as an important factor that contributes positively to the caregivers' well-being (Broodryk, 2014:7-8).

Murphy et al. (2007:184) found that caregivers of children with disabilities coped with the daily responsibilities by taking 10 to 15-minute breaks, taking mini-naps, or just sometimes 'having a good cry'. They found that caregivers' relaxation methods included shopping and the companionship of pets.

These findings correlated with the findings of Gray (2006:972) whose study focused on the coping strategies of parents of children with autism. The coping strategies that were identified by the participants were the use of treatment services (such as the centre for persons with autism, special schools, respite care, private carers, etc.), family support, religion, social withdrawal, philosophical perspectives, emotional reactions, routines and contact with other parents.

In a study conducted in Pakistan with individuals who had a child with a severe learning disability with or without additional physical or sensory disabilities, several coping strategies were identified. These were: sharing care with others in the immediate family, accepting support from the extended family, being proactive in taking control of the child's care, maintaining interests outside the home, avoiding difficult situations by not taking the disabled child to crowded places, changing their ideas about disability, inner conviction in the initial stages of the child's life that they should look after their child without external help, and finally, recognising the personal satisfaction they got from

taking care of their child, which strengthened their relationship (Croot, Grant, Mathers and Cooper, 2012:1543).

A study in 2009 examined what coping strategies are used by parents of children with and without disabilities. The eight types of coping strategies identified in the study are planful problem solving, seeking social support, confrontive coping, distancing, self-control, escape avoidance, accepting responsibility, and positive reappraisal. This study found that parents of children with disabilities preferred different coping strategies than parents of children without disabilities, since each of the eight coping strategies was used more often by parents of children with disabilities whereas parents with children without disabilities might only use some of these strategies (Paster, Brandwein and Walsh, 2009:1341).

Taanila, Syrjälä, Kokkonen and Järvelin (2002:82) conducted a study on the coping of parents with physically and/or intellectually disabled children. In their study, they compared the coping mechanisms of high-coping families to the coping mechanisms of low-coping families. With high-coping families, coping mechanisms such as acceptance, optimistic attitude, positive feelings, good family cohesion, good cooperation, open communication, good social support, self-confidence, information, openness, and flexibility were identified. In low-coping families, it was found that most coping mechanisms were only used by mothers. There were serious disagreements in accepting the child's disability between parents: fathers tended to have hoped that the child's disability would disappear. This led to marital relationships not being very good. It was further found that it was mainly the mothers who got minimal social support from social relationships. Elliott et al. (2002:691) claim that mothers tend to be the ones that try to maintain family cohesion. Family members may shift in their own adjustments and abilities to cope with the caregiving demands, which affects the person with the disability's ability to cope.

Grant et al. (2006:343) note that review of cross-sectional studies suggests social support is a significant predictor of depression and life satisfaction at the onset of the caregiver role. On the other hand, social support benefits may extend on the long-term, generating better energy, mental health, physical function, general health, quality of life, and less

pain. Higher levels of social support were associated with lower levels of caregiver depressive symptoms and higher levels of well-being and general health. Interventions that provide social support and assist caregivers in developing a more adaptive orientation may benefit family caregivers after their return to the community.

From these studies, various coping strategies of family caregivers of persons with disabilities have been identified. These strategies help the family caregivers adjust to the caregiving lifestyle. These coping strategies were further investigated through the empirical study to derive conclusions on what type of coping strategies are used by family caregivers of persons with physical disabilities.

## **2.8 CONCLUSION**

Due to the lack of comprehensive previous research on the support needs and coping mechanisms of family caregivers of persons with physical disabilities, similar research findings were used as a precedent for this study. There already seemed to be a connection between the family caregivers of persons with different disabilities, so there was a high likelihood that similar findings would be made during the empirical study. The information received from similar research was used as a framework for the questionnaire that was used for the interview schedules in the empirical study.

## **CHAPTER THREE**

### **THE SUPPORT NEEDS AND RESOURCES AVAILABLE TO FAMILY CAREGIVERS OF PERSONS WITH PHYSICAL DISABILITIES**

#### **3.1 INTRODUCTION**

In the previous chapter the experiences of family caregivers of persons with physical disabilities were discussed, including negative experiences and barriers experienced by them. This chapter builds on the previous one by discussing the support needs of family caregivers of persons with physical disabilities, which relates to the second objective of this study. This objective was achieved in the study through investigating the general support needs and then looking at their support needs in terms of Pelentsov et al.'s (2015) support needs framework for parents as well as Bronfenbrenner's ecological perspective.

#### **3.2 SUPPORT NEEDS OF FAMILY CAREGIVERS OF PERSONS WITH PHYSICAL DISABILITIES**

When caring for a person with a physical disability, family caregivers may experience certain specific needs.

Hartley et al. (2011:139) identified common types of assistance and support services for persons with disabilities and their families. These services include community support and independent living, residential support services, respite services, support in education or employment, communication support, community access, information and advice services as well as assistance animals. Pelentsov et al. (2015:489) conducted a study on the support needs of parents of children who have a rare disease. According to these authors, the needs can be categorised into social, informational, emotional, practical, physical, spiritual and psychological needs. These needs can be met through various role players.

People with disabilities may require a range of services. Unmet needs for support may include personal care, access to aids and equipment, participation in education, employment, and social activities and modifications to the home or workplace (Hartley et al., 2011:41).

### **3.2.1 Previous research findings on support needs of family caregivers**

In 2009, nearly 66 million Americans (30% of households in the USA) reported that they provided unpaid care as a family caregiver (Collins et al., 2011:1309).

Parents of children with disabilities are also perceived as having particular needs – the need for information, advice, support and practical help. The needs of parents are addressed through a combination of informal social support networks, including friends and family, voluntary organisations, and statutory parent partnership services. However, for many parents their needs are less likely to be met than those of their child and may stay unmet (Russell, 2003:144-145). The same can apply where the person with the disability is an adult. The main unmet needs of caregivers from this study are home safety, emotional and physical stress management, and finding easy activities to do with the care recipient whilst having enough time for themselves (Collins et al., 2011:1309).

In *Children with Disabilities in South Africa: A Situation Analysis: 2001-2011* (DWCPD and UNICEF, 2012:22) it is stated that social support to persons with disability should include tracking developmental milestones, teaching independence, and caring for children. The report emphasises that for parents to be able to care for and support their children, parents need to know their rights and responsibilities and what resources are available to them. Parents need to be given information if they are to make informed decisions about the development and education of their children. Information must be given in various ways that take parents' cognitive abilities into consideration. Furthermore, this report states the importance of disability and diversity awareness programmes for social cohesion.

Hartley et al. (2011:139) identified common types of assistance and support services for persons with disabilities and their families. These services are summarised in Table 3.1 on the next page.

**Table 3.1:** Types of assistance and support services for persons with disabilities and their families

NEED	SPECIFICATION/EXAMPLE
<b>Community support and independent living</b>	Assistance with self-care, household care, mobility, leisure, and community participation
<b>Residential support services</b>	Independent housing and congregate living in group homes and institutional settings
<b>Respite services</b>	Short-term breaks for caregivers and people with disabilities
<b>Support in education or employment</b>	A classroom assistant for a child with a disability, or personal support in the workplace
<b>Communication support</b>	Sign-language interpreters
<b>Community access</b>	Day-care centres
<b>Information and advice services</b>	Professional support, peer support, advocacy, and supported decision-making
<b>Assistance animals</b>	Dogs trained to guide people with a visual impairment

**Source:** Hartley, Ilagan, Madden, Officer, Posarac, Seelman, Shakespeare, Sipos, Swanson and Thomas (2011)

### 3.2.2 Parents' supportive care needs framework

In their a study on the support needs of parents of children who have a rare disease, Pelentsov et al. (2015:489) identified their needs as follows: social, informational, emotional, practical, physical, spiritual and psychological needs. These needs could also be true for any other family member that takes care of the person with the physical disability (Palisano, Almarsi, Chiarello, Orlin, Bagley and Maggs, 2010:86). In Table 3.2. on the next page, Pelentsov et al.'s Parents' supportive network and its elements are laid out.

**Table 3.2:** Framework for support needs of parents of children with a rare disease

<b>TYPE OF NEED</b>	<b>EXAMPLES</b>
<b>EMOTIONAL NEEDS</b>	Stress and anxiety Guilt and blame Uncertainty and worry Anger and frustration Powerlessness Shock and denial Fear
<b>PRACTICAL NEEDS</b>	Finances Work and employment Respite and leisure Accessing services and support Childcare and other carers Transport Home modifications
<b>PHYSICAL NEEDS</b>	Health problems associated by parent also having the disease Fatigue and exhaustion Poor sleep Loss of appetite and weight loss Headaches Frequent illness
<b>INFORMATIONAL NEEDS</b>	Information is easy to access and is relevant Early and definitive diagnosis Information on child's illness Resources for family and friends Child's future health needs Available services
<b>SOCIAL NEEDS</b>	Isolation and loneliness Family and friends' support Health-care professional partnerships Work/life balance Partner and siblings' relationship Social expectations
<b>SPIRITUAL NEEDS AND PSYCHOLOGICAL NEEDS</b>	Depression and anxiety Stress Coping Self-worth

**Source:** Pelentsov, Laws and Esterman (2015:489)

### 3.2.2.1 Emotional needs

Pelentsov et al., (2015:489) stated note that parents tend to experience the initial diagnosis period of their child, as very emotional. They found that parents felt emotions such as shock, distress, anger, fear, disbelief, denial and guilt. Signs of stress were apparent through anxiety, uncertainty, worry, fear, frustration, grief, powerlessness, shock and denial. Parents also seemed to be, overwhelmed with sadness, and feelings of vulnerability, and suffered from anticipatory loss, blame, confusion, disbelief, dismay, helplessness, insecurity and a lack of control.

### 3.2.2.2 Practical needs

With regards to practical needs, Pelentsov et al., (2015:489) found that parents emphasised financial matters as one of their main practical needs. they require. Many parents reported increased financial difficulties associated with their child's condition and continuous care needs. Because the child needs care, mothers, especially, might have to reduce or even quit their full-time employment to see to the child's care needs. for the child. This means that a family might have shifted from a dual-income to a single-income family. Another practical need that was identified is the planning and coordinating of care and services to meet their child's unique care needs.

### 3.2.2.3 Physical needs

Caring for their child often caused parents to experience physical and mental exhaustion, sleep disturbance, fatigue, loss of appetite, weight loss, headaches, dizziness and frequent colds (Pelentsov et al., 2015:489). This could be in line with physical health issues discussed in Chapter Two.

### 3.2.2.4 Informational needs

It was also found that parents had a need for general medical information – information concerning their child's future health and life chances and the impacts their child's disease and prescribed medications would have on the child's development, learning and long-term health. They also needed information on what long-term services and community health resources were available for them to use currently as well as in the future (Pelentsov et al., 2015:489).



Very few caregivers can afford to devote the time and energy necessary for comprehensive education and training prior to assuming their role as primary caregiver. Most rehabilitation programmes have printed educational materials available for caregivers to read but insufficient hands-on training to assist family caregivers in their role (Elliott and Pezent, 2008:6). Collins et al. (2011:1309-1317) reported in their study that most caregivers indicated that they needed more information about support services (77%) and due to the lack of information they were most likely to use the Internet (29%) or their doctors (28%) as primary sources of additional caregiving information.

In research involving families of children with physical disabilities, parents most often expressed needs for information about services (59%) and their child's condition (43%). Mothers of children with CP identified needs for both formal and informal support and information about community resources. The health professionals' role is to assist families in preparing for key periods in their children's lives, that is children's transition to preschool, elementary education, secondary education and adulthood (Palisano et al., 2010:86).

#### 3.2.2.5 Social needs

Pelentsov et al. (2015:489) found that parents identified support groups, families and friends as providing support but that it is not sufficient as the support tends to get less as time passed.

#### 3.2.2.6 Spiritual and psychological needs

Pelentsov et al. (2015:489) found that some parents experienced a crisis of faith due to their not feeling connected or 'belonging' to a church community because of their child's disease. The psychological needs of parents included the need for psychological support or mental health counselling to address their feelings of uselessness, powerlessness, helplessness, stress and shock.

From these observations, they decided to formulate their own framework that would encompass the support needs of parents whose child has a rare illness. Although the

study was not focused specifically on family caregivers of persons with a physical disability, it still acted as a useful guide to predict possible outcomes for this study.

### **3.3 OVERVIEW OF BRONFENBRENNER'S ECOLOGICAL PERSPECTIVE**

Bronfenbrenner's model (1979:3) of community levels, later known as the ecological perspective, proposed that there is a series of nested systems, fitted into one another. The four levels that Bronfenbrenner identified are the micro-, meso-, exo- and macrosystem (Visser, 2007:25). The ecological system's theory provided by Bronfenbrenner emphasises that all individuals, including children, develop within a context of environmental influences that have either a direct or an indirect influence on them (Harris and Graham, 2010:10). This ecological context consists of different intra-familial and extra-familial systems.

From this ecological perspective, families are seen as social environments that could be improved through public intervention. Furthermore, there are social institutions outside of the family that influence both the family and the child, including public programmes and services (Leiter, 2004:6). The social ecological perspective extends beyond the legal guardian and person with physical disability relationship to include personal and social caregiving (Kahana, Biegel and Wykle, 1994). According to this perspective there are various other social institutions outside the family that could influence both the family and the child (Leiter, 2004:6). This includes the exchanges between people and their physical and social environments (Koopman, 2003:5).

Ross and Deverell (2010:258) quote Bronfenbrenner in saying that "the family is the most effective and economical system for fostering and sustaining the development of the child. . . The involvement of the child's family as an active participant is critical to the success of any intervention program." These authors identified several subsystems within the family systems theory, namely the marital subsystem, the parental subsystem, the sibling subsystem and the extended family subsystem. In the current study, Bronfenbrenner's ecological perspective was used to further examine the different support systems to family caregivers. A brief discussion follows below.

It is very unlikely that a single service provider or institution can adequately and efficiently address caregiver needs, as these needs are dynamic and evolving, subject to change related to the physical, psychological, social and financial resources of the caregiver and in the resources and disability degree of the care recipient (Elliott and Pezent, 2008:2). It is therefore important that family caregivers get support at most levels of Bronfenbrenner's ecological model, that is, the micro, meso, exo- and macrolevels. The four levels of Bronfenbrenner's model will be discussed further by referring to previous research on similar studies and adapting it to the relevance of this study.

The microsystem consists of the immediate family environment. The mesosystem refers to interconnections between two or more interactions outside the family environment, such as school and peer influences. The exosystem is the community context that may not be directly experienced by the child, but which may influence the elements of the microsystem, such as sibling interactions. The macrosystem is the wider social, cultural, and legal context that encompasses all the other systems (Xu and Filler, 2008:55).

### **3.3.1 Microsystem**

The microsystem is the most intimate and closest system to a person (Parker, 2011:41). Proximal interactions take place within this system and refer to the face-to-face, long-term relationships (Donald, Lazarus and Lolwana, 1997:231). For family caregivers of persons with physical disabilities, this system could include spouses, other family members or very close friends.

### **3.3.2 Mesosystem**

The set of links between microsystems can be defined as the mesosystem. The stronger and more diverse the interactions between the microsystems, the greater positive influence the mesosystem will have on the person (Nash et al., 2005:37). This may be referred to as the local neighbourhood or community (Donald et al., 1997:231).

For family caregivers with physical disabilities, these systems could include extended family, professional service providers and other friends. Goldner and Drentea (2009:501) explains that the term 'personal caregiving' acknowledges that other family members may assist the primary caregiver and that formal services (professionals) may

supplement these informal forms of support

### **3.3.3 Exosystem**

The exosystem consists of the interconnections between the micro- and mesosystems. These also include the settings or systems with which the individual does not necessarily have direct contact, but which may affect their experience of these two systems (Chetkow-Yanoov, 1997:11; Visser, 2007:25). The term 'social caregiving' acknowledges that caregiving affects other social relationships. The social ecological perspective emphasises that the context in which caring for persons with a disability takes place must also be examined (Goldner and Drentea, 2009:501). The community level can be described as having multiple components that influence the micro- and mesosystems. The exosystem may include medical, educational and recreational resources and even the media that would also influence the individual (Wait, Meyer and Loxton, 2005:42). For family caregivers of persons with physical disabilities, the exosystem can include any community service that influences their social interactions.

Examples of exosystems would be the education system, health services, the media, the parents' places of work, or community organisations (Donald et al., 1997:231).

### **3.3.4 Macrosystem**

The macrosystem is the wider system of ideology and the organisation of social institutions. This includes views on gender roles and social class, cultural values, as well as the attitudes and values of people and policies that regulate behaviour (Scileppi et al., 2000:47; Visser, 2007:25). Cultural influence exists in all contexts within the ecological systems. It guides a person's inherent thoughts and feelings towards a specific experience as well as one's behaviour during social interaction (Xu and Filler, 2008:66).

## **3.4 SOCIAL SUPPORT AVAILABLE TO FAMILY CAREGIVERS OF PERSONS WITH PHYSICAL DISABILITY AT THE DIFFERENT LEVELS PRESENTED BY THE ECOLOGICAL PERSPECTIVE**

Bronfenbrenner's model focuses on aspects such as social support, environmental barriers and social stereotypes that influence the individual. According to this

perspective, development occurs as the result of individuals being embedded within “a set of nested structures, each inside the other like a set of Russian dolls”. As mentioned earlier, the different levels of this model include the microsystem (activities and interaction patterns in individuals’ immediate surroundings), the mesosystem (connections among microsystems), the exosystem (settings that do not contain the individual directly, yet still affect them) and the macrosystem (broader systems of values, laws, customs, and resources) (Greenfield, 2011:3).

Social support has been associated with well-being among persons with acquired disabilities (Elliott et al., 2002:2). Previous research has identified social support as a temporary need, although social support for persons with disabilities and their families might require support to be provided over longer periods of time (Devereux, Bullock, Gibb and Himler, 2015:508).

Blanes et al. (2007:401) found that family caregivers who received support reported more satisfaction with their lives than those who were not receiving help. It is, therefore, relevant to discuss the support needs of family caregivers of persons with physical disabilities at the various levels of the ecological perspective.

### **3.4.1 Microsystem**

The microsystem refers to family caregivers themselves and their closest relationships with other people, such as other family members (Russell, 2003:145). For family caregivers of persons with physical disabilities, the microsystem might be made up of spouses, other family members or very close friends. Informal support from friends and relatives is regarded as essential for caregivers to manage everyday life (Taanila et al., 2002:82).

Murphy et al. (2007:184) found that parents typically only spent time with other family members after the child with disabilities had fallen asleep. They further noted that the impact of caregiving on marital relationships varied, with some participants suggesting that their experiences had brought them closer together, with open communication and sharing of responsibilities. However, many other parents acknowledged some conflict regarding how to raise their children. A small percentage (10%) of marriages that

formed part of the study had ended in divorce. Parents who had adopted children with disabilities were generally more emotionally stable because they were prepared for the challenges of caregiving (Murphy et al., 2007:184).

### **3.4.2 Mesosystem**

Extended family members, professional service providers and other friends can form part of the mesosystem of family caregivers of persons with physical disabilities. Family caregivers of disabled children might generate insensible expectations of people delivering support needs services to children with disabilities and their families. Such caregiver might not realise these expectations, with the result that they cannot be fulfilled. It is vital that the expectations require thought and preparation. Each party might have different expectations, and trust can only develop between them if clear goals and responsibilities are articulated, communicated, discussed and negotiated. On the other hand, where trust in a relationship is broken, caregivers might expect fewer positive outcomes. Problematic relationships between caregivers and professionals that result in conflict and distrust can lead to anxiety and depression, which many caregivers of people with disabilities suffer from (Russell, 2003:145).

The education of persons with physical disabilities requires a multi-disciplinary team effort. The team can be made up of paediatricians, neurologists, physiotherapists, occupational therapists, speech clinicians, nurses, orthopaedic surgeons, vision specialists and social workers. Families of children with physical disabilities must be the central focus of the educational process. This multi-disciplinary team support enables families to adjust more easily to the demands of raising a child with physical impairments (Correa, 2013:1062).

Dorsett (2010:83) believes that social workers can also play a vital role in the rehabilitation team of persons with physical disabilities by providing information, reassurance, exploring meaning and appraisals, and the development of problem-solving skills. They also play a further role in facilitating access to necessary resources through interventions such as advice, referral, and advocacy that assist both the person with the disability and his/her family.

#### 3.4.2.1 Health-care professionals

As indicated above, physiotherapists, occupational therapists, speech therapists, developmental paediatricians, neurologists and orthopaedic surgeons are among the health professionals who provide services to children/youth with CP (and other physical disabilities) (Palisano et al., 2010:90).

Within the South African health-care system public (free, government-funded) health care and private (expensive, patient- or insurance-paid) health care exists. The Health Systems Trust reported that only about 25% of the Health Professions Council of South Africa (HPCSA) registered occupational therapists and 17% of physiotherapists between 2007 and 2011 was working in the free, public sector (DWCPD and UNICEF, 2012:60). This creates a problem in terms of accessibility of health professionals as most of the population cannot afford private practitioner fees. Patients who go to public health care might experience long waiting periods because the patient-to-practitioner ratio is bigger in public health care than private health care in South Africa.

In a study, *Children with Disabilities in South Africa: A Situation Analysis between 2001 and 2011* (DWCPD and UNICEF, 2012:60), stakeholders in the health sector reported a critical shortage of specialists for assessment of children (e.g. neuro-developmental paediatricians). Various challenges for human resource availability were a high vacancy rate for rehabilitation therapists, the fact that therapists at the primary health care level have very little time for rehabilitation, and urban therapists' struggles to cope with the challenges and realities of children with disabilities living in rural areas.

#### 3.4.3 Exosystem

When looking at how community resources (within the exosystem of this theory) could support family caregivers of persons with physical disabilities, it is evident that personal support workers (better known as home-based carers in South Africa) play a vital role in community-based service systems, but there is a shortage of such workers in many countries (Hartley et al., 2011:144).

Some hospitals also provide adaptive training courses. In the study by Taanila et al. (2002:82), most of the parents noted that the conversations and the exchange of experiences during these courses with other parents who had a child with a similar disability had been very rewarding. Parents of children with disabilities might rely on these peer support groups, especially if they have no or limited other formal support structures.

Some children with disabilities may be fortunate to be part of an educational institution where parents or other family caregivers can get additional formal support (King, Baldwin, Currie and Evans, 2005:196). Educational institutions for persons with disabilities in South Africa include special care centres, special schools and full-service schools. The DBE in South Africa indicated that their education management information systems data from annual school surveys found that there was an increase in inclusive education facilities in South Africa between 2008 and 2011. Special schools increased from 413 (2008) to 423 (2011), special schools with hostel facilities increased from 219 (2008) to 261 (2011), special schools converted to resource centres from 30 (2008) to 120 (2011), special schools with Grade R increased from 112 (2008) to 134 (2011) and full-service schools increased from 30 (2008) to 513 (2011) (DWCPD and UNICEF, 2012:60).

In a news article in 2017 (Levy, 2017) it was reported that the number of children with disabilities receiving some form of education has almost doubled over the last 15 years. It was estimated that there are 464 special schools in South Africa and another 715 ‘full-service’ schools that make provision for children with disabilities. Furthermore, the DBE had reached its target of placing more than 240 000 such learners in schools in 2015.

#### 3.4.3.1 Special care centres

Redfern (2013:21) conducted a study on disability in Cape Town. He defined special care centres as institutions that cater for children with disabilities who cannot be accommodated within special schools. According to the author, most of these centres are private organisations.



#### 3.4.3.2 Special schools

Special schools are schools that cater for learners whose special educational needs cannot be met in a mainstream or full-service school. These schools cater for a specific special need, for example cerebral palsy, autism, moderate intellectual disability, to name a few. These schools may follow the national or alternative curriculum and tend to focus on practical rather than academic subjects at high school level (Redfern, 2013:21).

#### 3.4.3.3 Full-service schools

Redfern (2013:21) defined full-service schools, in accordance with the South African Department of Education in June 2005, as mainstream education institutions that provide education to all learners by catering for their comprehensive learning needs.

### 3.4.4 **Macrosystem**

Persons with disabilities and their families are confronted with many barriers and limitations imposed by social, political and cultural factors (Dorsett, 2010:83) as well as educational and economic factors (Ben-Zur, Duvdevany and Lury, 2005:59). Managing and dealing with disability requires a political response to help re-organise and re-build society to allow persons with physical impairments to participate as equal members of society (Gretschel, 2016:9). Resources that assist in overcoming these aspects, form part of the macrosystem (DWCPD and UNICEF, 2012:22). Some examples are disability benefits, cultural norms and attitudes, education system, policies and legislation and health care.

Activists and organisations that advocate for the welfare of disabled persons have been advocating for social change in disability sensitisation. They advocate a change from the dominant view regarding disability, based on the ‘medical’ model, to a ‘social’ model of disability. This encourages the removal of barriers created by society that prevent people with disabilities to fully participate.

#### 3.4.4.1 Disability benefits

Disability benefits, in cash and in kind, paid for by governments and delivered through various public programmes assist persons with disabilities and their families. Nearly

all countries have some type of public programmes targeted at persons with disabilities. These programmes may include services such as health and rehabilitation services, labour market programmes, vocational education and training, disability social insurance (contributory) benefits, social assistance (non-contributory) disability benefits in cash, provision of assistive devices, subsidised access to transport, subsidised utilities, various support services including personal assistants and sign language interpreters, together with administrative overheads (Hartley et al., 2011:43).

*a) Care dependency grant*

The care dependency grant (CDG) is a social grant provided by the South African Social Services Agency (SASSA) to the family member responsible for the care of a disabled child. In order to qualify, the child must be severely disabled and require full-time and special care and must be younger than 18 years, and households must earn below a certain amount (Redfern, 2013:21).

The amount for this grant was fixed at R1 505 per month per child during the 2016/2017 budget but has been increased by 6.3% in the 2017/2018 budget to R1 600 per child with a disability (National Treasury, 2017). There has been a steady increase in the number of adults and children with disabilities who have access to social security (grants). In 2011, it was reported that of the CDGs that were issued, most went to KwaZulu-Natal (30%) and the least amounts were distributed to the Free State and the Northern Cape (both 4%). The rest of the CDGs were distributed as follows: Eastern Cape (17%), Gauteng (12%), Limpopo (11%), Mpumalanga (6%) and North West (8%). The Western Cape only received 8% of the care dependency grant (DWCPD and UNICEF, 2012:22).

*b) Assistive devices*

Persons with physical disabilities may need to use various assistive devices to make their adjustment in the community easier. These assistive devices may include a wheelchair, walking stick/frame, hearing aid and spectacles. It was

reported (Statistics South Africa, 2014) reported that in persons over the age of five years, the assistive aid that was used the most were eye glasses used by 21.4% of this population group in South Africa and 2.8% in the Western Cape respectively. Other assistive devices such as wheelchairs, walking sticks/frames or hearing aids were only used by 2% to 3% of the population group in both South Africa and the Western Cape.

c) *Personal income tax benefits*

The South African Revenue Service (SARS) also supports persons with disabilities and their families by allowing them to claim 33.3% of the qualifying out-of-pocket medical and disability-related expenses, paid during the relevant year of assessment. Any taxpayer who has a disability or whose spouse or child has a disability in accordance with the criteria set out in the ITR-DD form, confirmed by the medical practitioner, is eligible for these claims (RSA Government, 2016).

SARS defines physical impairment as the restriction on the person's ability to function or perform daily activities after maximum correction which is less than a 'moderate to severe' limitation. A taxpayer who has physical impairment or whose spouse or child has such impairment may still claim certain qualifying prescribed expenses. There is, however, a limitation for taxpayers to be below 65 years (SARS, 2016).

SARS has prescribed a list of physical impairment or disability expenses. These expenses include personal attendant care expenses; travel and other related expenses; insurance, maintenance, repairs and supplies; prosthetics; aids and other devices; services; continence products; service animals; and alterations or modifications to assets acquired or to be acquired (SARS, 2012).

The taxpayer is also entitled to the medical scheme fees tax credit in respect of contributions made to a registered medical scheme. A person with a disability or whose spouse or child has a disability can claim 33.3% of the fees paid to a medical scheme or qualifying foreign fund as exceeds three times the

amount of the medical scheme fees tax credit to which that person is entitled (SARS, 2016).

#### 3.4.4.2 Cultural norms and attitudes

Cultural beliefs and attitudes concerning disability determine the social values bestowed upon caregivers of persons with disabilities that have an impact on any interaction they might have (Russell, 2003:145).

Some cultures have different beliefs regarding the responsibilities of taking care of family members with disabilities. Blanes et al. (2007:403) reported that in Brazil it is part of the culture to provide total support to relatives with disabilities.

Masasa (2002:1) found that some black people blamed disability on witchcraft and that they consulted health professionals and folk healers and looked to God for healing, whilst most of the white and coloured people believed that disability is a result of natural causes, human error or the will of God. Asian parents tended to attribute the cause of a child's disability to supernatural influences or sins committed by the child's ancestors or parents. Cultural norms and expectation of family responsibility, such as among Hispanics, are more common among coloured people than white people, where it is believed that they should be embracing caregiving as a privilege (Goldner and Drentea, 2009:501).

Most of these notions are based on preconceived ideas, which include shame and feelings of obligation toward the child with special needs. It has been noted that positive interactions when raising a child with special needs had a significant moderating effect on the relationship between the child and parental well-being (Qayyum, Lasi and Rafique, 2013:132).

#### 3.4.4.3 Policies and legislation

Policies and legislation play a pivotal role in service delivery to persons with disabilities and their families. There are various policies both internationally and nationally that provide support:

a) *Convention on the Rights of Persons with disabilities*

During the Convention on the Rights of Persons with disabilities, 155 countries signed the convention, 128 endorsed the convention, 91 signed the protocol and 76 endorsed the protocol. South Africa signed and endorsed the convention and signed and endorsed the protocol (UNICEF, 2013).

b) *International Classification of Functioning, Disability and Health (ICF)*

The ICF focuses on the ‘components of health’ rather than on the consequences of disease. The ICF approach covers all aspects of health and describes them in terms of health-related domains. It is intended to be a universal classification system, meaning that it covers all people, not just people with disabilities. Two significant additions were made to the original Classification of Impairments, Disabilities and Handicaps model, reflecting the social construction of disablement as well as personal factors. The WHO encourages the application of the ICF internationally as a classification tool and a framework for social policy, research, education, and clinical practice (Rosenbaum and Stewart, 2004:5-7).

c) *Constitution of the Republic of South Africa*

The Constitution of the Republic of South Africa (hereafter referred to as ‘the Constitution’) recognises that people with disabilities have been discriminated against based on their disability and that the creation of equity for them entails redressing past inequity.

This policy framework draws on the central principles of equity and non-discrimination. These values and principles are entrenched in various other policy documents relevant to people with disabilities, such as the Integrated National Disability Strategy, the Education White Paper 3 on the Transformation of the Higher Education System, the National Plan for Higher Education, and the Education White Paper 6, the Promotion of Equality and Prevention of Unfair Discrimination Act, the Department of Public Service Administration’s Batho Pele (‘People First’) principles, the Disability Rights

Charter, the National DoH's Patient's Rights, the National Rehabilitation Policy, the Standardization of the Provision of Assistive Devices in South Africa: Guidelines for Use in the Public Sector (Disability – Specific) and Free Health Care for People with Disabilities at the Hospital Level (Disability – Specific) (Greyling, 2008:3). The White Paper for the transformation of the health system in South Africa also plays a role in service delivery to persons with disabilities and their families.

d) *The White Paper on an Integrated National Disability Strategy of 2000, South Africa*

The White Paper on an Integrated National Disability Strategy of 2000 covers various disability issues such as integration of disability issues in all government development strategies, planning, processes and programmes; as well as an integrated and coordinated management system for planning, implementation and monitoring in all spheres of government. One of its strategies is to improve health services to enhance prevention of disability (secondary prevention and complications thereof). It also seeks to ensure access to basic rehabilitation, and emphasises that appropriate, accessible and affordable health services are essential to the equalisation of opportunities for people with disabilities (Office of the Deputy President, 1997).

e) *Integrated Service Delivery Model, South Africa*

This policy paper lays out the main responsibilities, values, principles and services within the Department of Social Development. This document points out that the primary target groups of the Department are the poor and vulnerable sectors of the community, including people with disabilities and those with other special needs (Department of Social Development, 2006).

There are various services that form part of the social service delivery model, including rehabilitation. Rehabilitation services are aimed at improving and maintaining the social functioning of clients whose functioning is impaired because of injury, disability or any chronic condition. In addition to improving

the quality of life of an individual, rehabilitation services are an effective way of reducing the demands on families and publicly funded support systems (Department of Social Development, 2006).

f) *Education White Paper 6, South Africa*

This policy is focused on inclusive education for everyone in South Africa with special needs. Some of the main points in this policy are the following:

- In collaboration with the provincial departments of education, primary schools will be identified and designated for conversion to full-service schools to expand provision and access to disabled learners within neighbourhood schools.
- All higher education institutions are required to ensure that there is appropriate physical access for all physically disabled learners, particularly for blind and deaf students.
- The Ministry will continue its discussions with all national community-based organisations, NGOs, organisations of the disabled, health professionals and other members of the public who will play a central role in supporting the building of the inclusive education and training system (Department of Education, 2007).

g) *White Paper for Social Welfare, South Africa*

This policy document states that there must be social welfare policies and programmes which provide for cash transfers, social relief, and enabling and developmental services to ensure that people have adequate economic and social protection during times of unemployment, ill-health, maternity, child-rearing, widowhood, disability and old age (Department of Social Welfare, 1997).

Social welfare services and programmes will promote non-discrimination, tolerance, mutual respect, diversity, and the inclusion of all groups in society including women, children, the physically and mentally disabled, offenders,

people with HIV/AIDS, the elderly, and people with homosexual or bisexual orientation (Department of Social Welfare, 1997).

Section 3 of this policy focuses specifically on people with disabilities. Although the document was written 20 years ago and statistics are not accurate anymore, there are some main points still relevant to this study:

- A national coordinated disability strategy will equalise opportunities in all spheres of social life, promote social integration and address poverty among people with disabilities.
- The Department of Welfare (now known as the Department of Social Development) will coordinate with other government departments to facilitate the access of people with disabilities to public buildings, and national building regulations will be reviewed.
- The Department of Welfare (known as Department of Social Development) will also raise public awareness to facilitate the integration of people with disabilities (such as people who are deaf and blind) into all spheres of social life.
- Community-based support services and facilities will offer the person and his/her family a wide range of opportunities and options to promote independent living and integration into community life. (Department of Social Welfare, 1997).

This policy emphasises community development, which is an important part of developmental social welfare and could also provide support to family caregivers of persons with physical disabilities (Department of Social Welfare, 1997).

These policies and legislation provide a good foundation for better service delivery to persons with disabilities and their families to support them.

#### 3.4.4.4 Education system

In 2011, the DBE completed the Guidelines for Responding to Learner Diversity in the Classroom which was introduced during the national orientation programme on



the National Curriculum Statement. The Department of Basic Education also appointed a ministerial task team to oversee the development of a curriculum for South African Sign Language, Grades R–12 (DWCPD and UNICEF, 2012:60).

The provision of maps of access routes, lifts, ramps and toilets would be useful to ensure accessibility of the campus. Attendant care is a service seldom offered by universities; the absence of such a service may cause problems for students who need assistance with using toilet facilities or eating. Rest rooms and toilets can be modified by installing hand rails, changing the handle or lock on the cubicle, installing lever taps, adjusting the position of the sinks, or lowering hand dryers. Parking for people with disability is often insufficient, far from buildings and lecture rooms or in a position close to a sidewalk, making it difficult to get in and out of a vehicle as a result of limited space for a wheelchair (Greyling, 2008:33).

#### 3.4.4.5 Health care

The South African health-care system is divided into public (government) health services, on the one hand, funded through taxes and private health care services, and, on the other hand, funded through medical schemes or out-of-pocket payments.

Both these types of health care have their benefits (advantages) and obstacles (disadvantages). Generally, the public health services are free but overcrowded with a limited number of resources for the number of patients they take care of. The private health services are expensive but have more resources available in terms of the number of patients they take care of. Medical schemes do aid with the payment of private health services but only cover services according to the patient's health plan. Another obstacle is that the medical scheme rates increase every year, which makes such schemes less accessible for a big portion of the population who may not be able to afford membership (Ngubo and Muller, 2015:90-97).

### 3.5 CONCLUSION

In terms of resources available to family caregivers of persons with physical disabilities, Bronfenbrenner's ecological model combined with Pelentsov et al.'s (2015) framework for support needs of parents can be useful in identifying both the met and the unmet

needs of parents. Different resources have been discussed in this chapter. According to the *Directory of Organisations and Resources for People with Disabilities in South Africa* (Langenhoven and Richmond, 2009), there are advocacy organisations, day-care centres, residential care, schools and various other support services for persons with disabilities and their families within the Western Cape. The directory may, however, be outdated, so the analysis of the empirical study in the next chapter will give a good indication of how families of persons with physical disabilities perceive their needs are being met.

## **CHAPTER FOUR**

### **ANALYSIS OF EXPERIENCES OF FAMILY CAREGIVERS OF PERSONS WITH PHYSICAL DISABILITIES IN THE EMPIRICAL STUDY**

#### **4.1 INTRODUCTION**

This chapter is built from the previous chapters and relates to the fourth objective for this study. Chapter Two described the experiences of family caregivers of persons with physical disabilities whilst Chapter Three discussed the support needs and resources available to family caregivers of persons with physical disabilities. This chapter presents the analysis of the experiences of family caregivers of persons with physical disabilities as done in the empirical study. This is done through looking at the identifying particulars, resources and experiences.

From these sections, five main discussion points could be identified, namely support services (resources) used, support services still needed, general experiences in taking care of persons with disabilities PwDs, barriers experienced in caring for PwDs, and coping mechanisms used in taking care of PwDs. These five themes are discussed in this chapter, based on the feedback provided by the participants of the study.

#### **4.2 RESEARCH METHODOLOGY**

The research methodology includes the research question on which the research was based on, the goals and objectives of the research study, the research design, the research approach, research instrument, research sample and data collection and analysis procedure.

##### **4.2.1 Research question**

Given and Munhall (2008:787) states that research questions indicate the theoretical and methodological focus of the researcher. The study originated from the research question:

*What are the experiences of family caregivers of persons with physical disabilities?*

During the empirical study, the focus was based on this question. However, in order to identify the social support needs of family caregivers of persons with physical disabilities the researcher also looked at what services were already being used.

#### **4.2.2 Goal and objectives**

The goal of this study was to gain a better understanding of the experiences of family caregivers of persons with physical disabilities. This goal was achieved by means of the following objectives:

- To discuss the experiences of family caregivers of persons with physical disabilities from previous research and studies;
- To use the ecological perspective to explore the different social support needs and services of family caregivers of persons with physical disabilities;
- To analyse the experiences of family caregivers of persons with physical disabilities on the social support services used, their support needs, general experiences, barriers and coping mechanisms; and
- To make relevant recommendations on how to improve social support to family caregivers of persons with physical disabilities.

#### **4.2.3 Research approach**

The research study used a qualitative approach with some elements of a quantitative approach with regard to identifying particulars of the participants. The qualitative approach of the study provided the research study with different ‘case studies’ as every participant would be able to provide comprehensive information on their experiences.

This approach gave the researcher the opportunity to listen to participants’ stories and experiences. The narrative of experiences of participants in turn provided more depth to the data collected and deeper discussions for analysis of the empirical study. This is very useful since not much previous research has been done on this topic recently, so the more detail provided by participants, the more comprehensive the discussion on the topic can be (De Vos et al., 2011:355).

#### **4.2.4 Research design**

The research study used a combination of descriptive and exploratory research design. De Vos et al. (2011:95-96) describe the aim of exploratory research as being able to gain insight into a phenomenon, situation, community or individual. Descriptive research can be described as a more intensive analysis of phenomena to gain a more comprehensive description (Rubin and Babbie, 2005:125).

The research study was explorative due to the lack of current research on the topic. Once the needs of family caregivers were identified, this aspect was further discussed in the interviews and therefore enhanced the descriptive nature of the research design. These two research designs were chosen because the researcher sought to gain a more comprehensive understanding of family caregivers' support needs.

A combination of deductive and inductive reasoning was used in this research study. Deductive reasoning occurs when the reasoning moves from general to specific findings. It moves from logically and theoretically expected findings to test whether the expected patterns occur (De Vos et al., 2011:48). This was done through the literature reviews (Chapters Two and Three) and comparing these patterns with the findings from the empirical study (Chapter Four). Inductive reasoning, on the other hand, is when reasoning moves from the specific to the general (De Vos et al., 2011:49). This was done when unanticipated findings were found during the empirical study and reference was made to previous research studies.

#### **4.2.5 Research instrument**

The data collection was done by means of a semi-structured interview schedule. This instrument, according to De Vos et al. (2011:352), is mainly used to gain a perspective of the participant's perception of the research topic at hand. For this study, the interview was done in either Afrikaans or English (depending on the preferred language of the participant).

This interview schedule consisted of mainly five sections, namely identifying particulars (the only section with close-ended questions), resources and social support (general), resources and social support (Bronfenbrenner's model), experiences related

to grief and other emotions, caregiver burden and coping mechanisms. This is in line with the approach followed in previous studies, as discussed in Chapters Two and Three.

#### **4.2.6 Research sample**

Interviews were conducted with a sample of 20 participants. The planned method of sampling was purposive sampling where a clear definition of the population and intended sample is prevalent (Given and Munhall, 2008:799). Due to the lack of participants, one of the participants was identified through snowball sampling. Snowball sampling can lead to the identification of more than one participant (De Vos et al., 2011:233).

In research sampling, universe, population and sample are used to help identify relevant participants. The universe includes all possible subjects that possess all the characteristics in which the researcher is interested in for the study to be conducted. The population refers to the total set out of which the individuals for the study are chosen from, whilst the sample refers to the subjects chosen to participate fully in the study (De Vos et al., 2011:110).

For this study, the universe of sampling included all the family members of persons with disabilities. The population was family caregivers of persons with disability identified by the Tygerberg APD in the Cape Town area. The criteria for inclusion for the sample were the following:

- Participants must be a family caregiver of a person with a physical disability.
- They must be caring for the person with the physical disability that is not due to old age.
- Participants must be living in the Cape Town area.
- Participants must also be able to understand and speak either Afrikaans or English.

The method used for sample selection was first to get permission from the organisation that delivers services to persons with disabilities and their families and asking them to identify possible participants. The Tygerberg APD agreed to work in partnership with the researcher for this research project. After meeting with the organisation, they

suggested that they set up the possible participants and send the contact details to the researcher of potential participants in the research study.

Once the researcher had received the contact details, she contacted the participants and asked them whether they would be willing participate in the research study. If they agreed, an interview date, time and place (either their home or the Tygerberg APD office) was set up. The researcher explained the purpose of the research telephonically and repeated this once she met the participants in person. The researcher then went through the consent to participate form with the participants and gave them time to read it before signing it. The researcher also explained the debriefing process. The interviews only commenced after the consent to participate forms were signed. Each participant kept a copy of the consent form.

#### **4.2.7 Data collection and analysis**

Data for the empirical study was collected through the semi-structured interviews with the 20 participants ( $n = 20$ ). The interviews lasted between 30 and 60 minutes (excluding the time it took for the researcher to go through the consent to participate form with the participant). The interviews were voice recorded, with the participants' permission. This provided the researcher the opportunity to listen to the interviews again and get a more comprehensive collection of data on the topics discussed (De Vos et al., 2011:359). These interviews were transcribed and saved as encrypted files. The results of the data collected are discussed in terms of themes, sub-themes and categories in Section 4.3.

The study used a denaturalistic approach to transcribing. Oliver et al. (2005:1273) describe denaturalism as the removal of unique elements of speech such as pauses and non-verbal factors which suggest that within speech there are certain meanings and perceptions.

#### **4.2.8 Data quality verification**

De Vos et al. (2011:419), point out that credibility and authenticity, transferability, dependability and conformability must be considered when establishing the candour of the qualitative research study.

When looking at credibility and authenticity, the researcher should question whether there is a match between the participants' views and the researcher's reconstruction and representation of the views (De Vos et al., 2011:419-420). This was done through member checking (see Annexure H) where participants were given the transcripts of their interviews to confirm whether this was an accurate representation of their interviews. The transferability of this study refers to whether the findings would be applicable to a similar situation (De Vos et al., 2011:420). The wide-spread identifying particulars of the participants discussed in Chapter Four could influence the transferability of the study in a positive way.

The variety in participants was a limitation for the detailed analysis, as discussed in Chapter One. However, it could also potentially indicate transferability of the study. In Chapter Five recommendations for similar studies are made. According to De Vos et al. (2011:420), the researcher must assess whether the research process was logical, well-documented and audited to ensure the dependability of the study. The research process was described in Chapter One. This process was also explained to the participants in the Consent to Participate forms (see Annexures C and D). De Vos et al. (2011:346) explain conformability as the alternative for objectivity. It implies that the study's findings could be confirmed by another study. Conformability of this study was ensured through means of literature control after each sub-theme and category discussed (as presented in this chapter) and by engaging an independent coder who confirmed the themes identified for this research study (see Annexure I).

## **4.3 PARTICIPANTS' IDENTIFYING PARTICULARS**

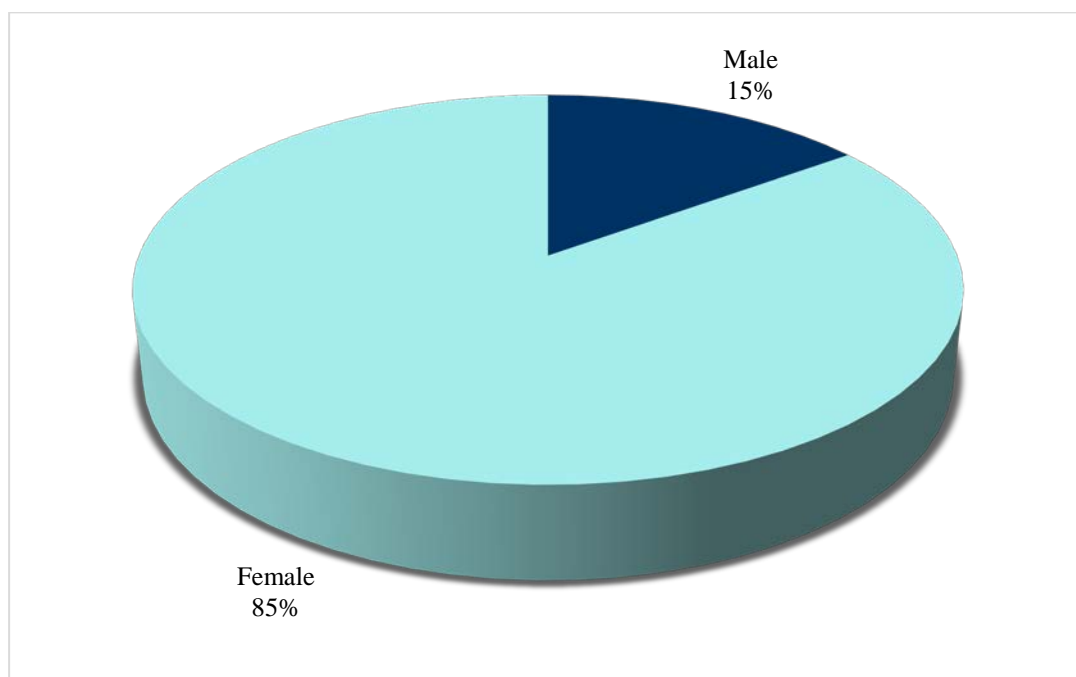
Although the study made use of qualitative data collection, some elements of quantitative data collection were used for the identifying particulars of the participants. This provided an overview of the different participants' life contexts.

### **4.3.1 Gender of participants**

Women are most commonly the caregivers, who provide care for periods ranging from months to decades (Blanes et al., 2007:401). Most of the research studies similar to this one focused mostly on a female perspective on caring for a person with a physical



disability since women were reported to be the main caregiver in most cases. As can be seen from Figure 4.1., this study also had males (siblings and parents) that took on a caregiving role, which potentially provides a more thorough insight into the social support needs of persons with physical disabilities.

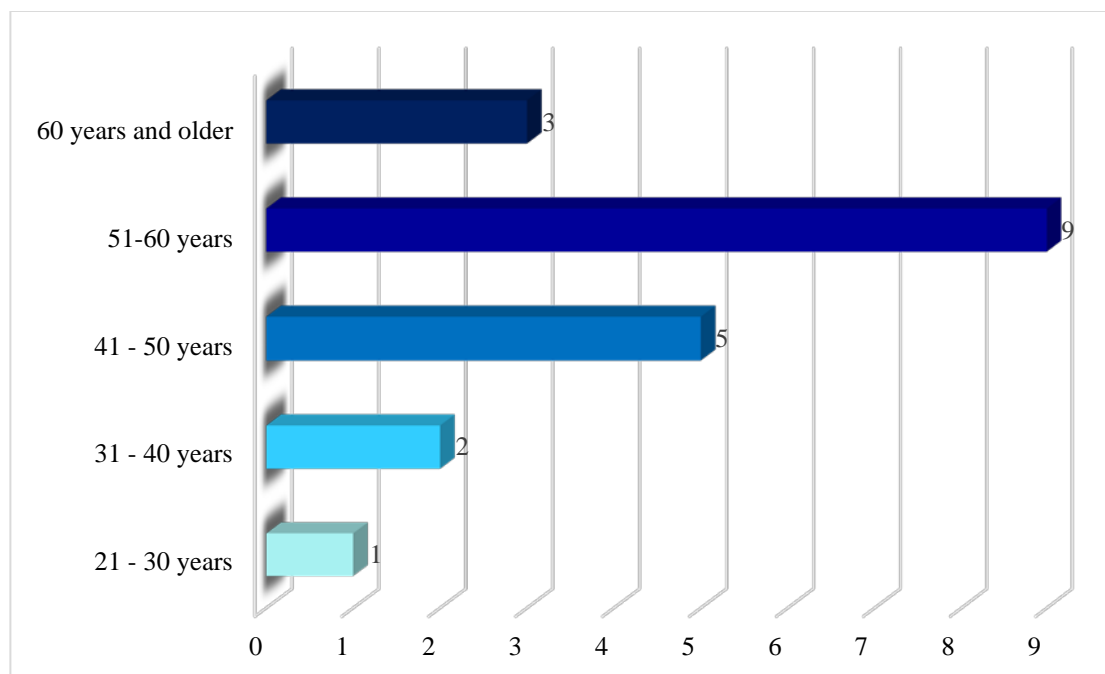


**Figure 4.1:** Gender of participants (n = 20)

Dingana (2012:111) also found in her study that the caregivers of people with physical disabilities were mostly females, thus potentially identifying a gap in research to be focused on male caregiving to persons with physical disabilities.

#### **4.3.2 Age group of participants**

Blanes et al. (2007:401) found in their study that the family caregivers to persons with disabilities were mostly aged between 29 and 68 years. In this study, the ages of the family caregivers (the participants) ranged from 27 to 75 years, which is more or less in line with what was found by Blanes et al. The exact age group distribution of the participants is shown in Figure 4.2 below.



**Figure 4.2:** Age group of participants (n = 20)

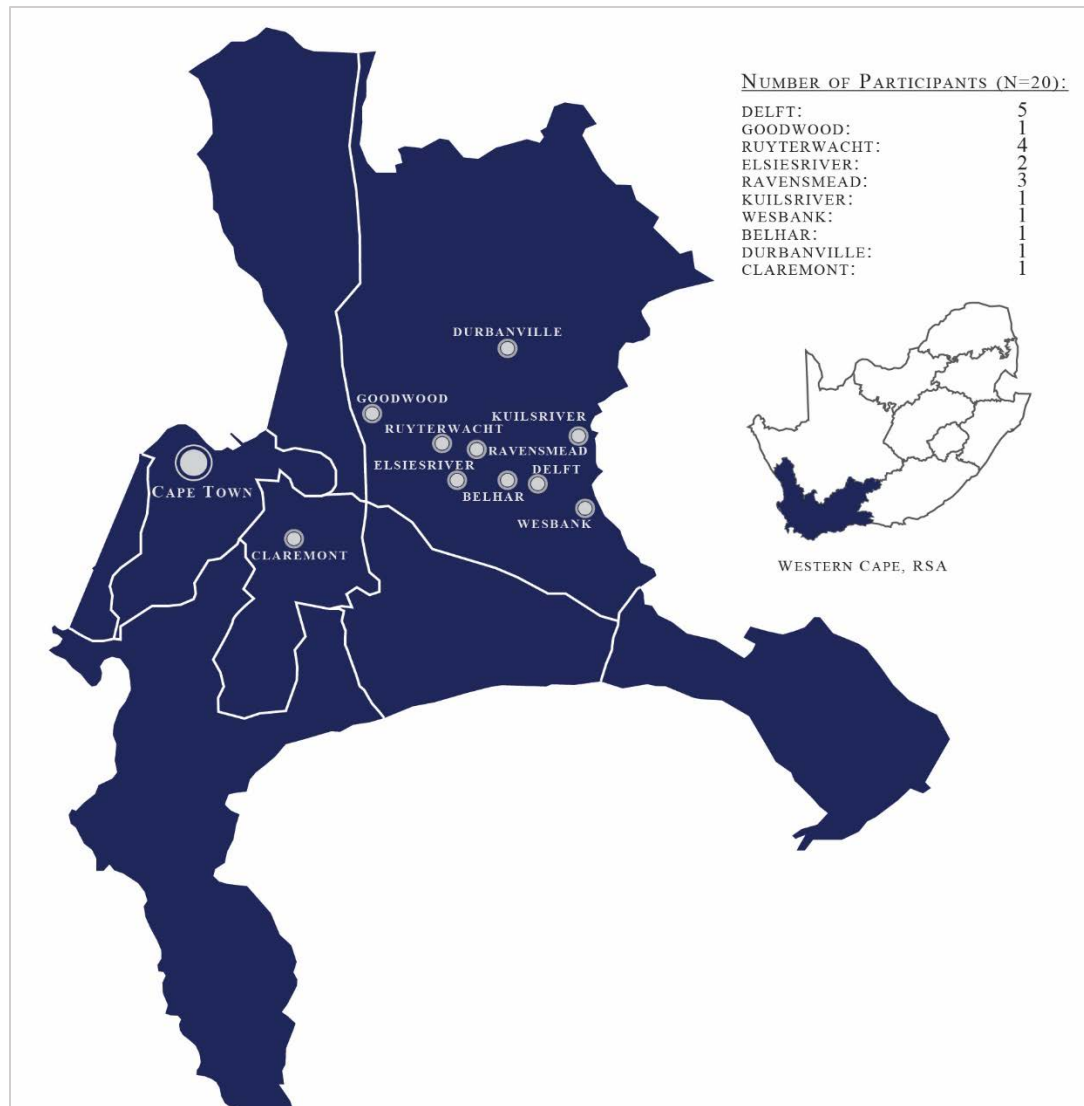
As can be seen from the figure above, the majority of the participants were in their fifties. All of them had adult children, which holds the risk for health issues as will be discussed in Sub-theme 4.2. later. In general, participants in the study of Murphy et al. (2007:184) felt that their (caregivers') own health suffered more when the child got older.

### 4.3.3 Living area of participants

In 2011, the WHO estimated that around 10% of the world's population (that being about 700 million people), were living with a form of disability (Hartley et al., 2011:139). According to the Census of 2011 (Statistics South Africa, 2014:8), there were 2 870 130 people with disabilities in South Africa, of whom 222 333 lived in the Western Cape.

Although the exact number of family caregivers of persons with physical disabilities in South Africa is not available, the prevalence of persons with disabilities indicates that there might be quite a significant number of family caregivers. The participants in this study lived in the Cape Town area (Figure 4.3) but the researcher aimed to cover

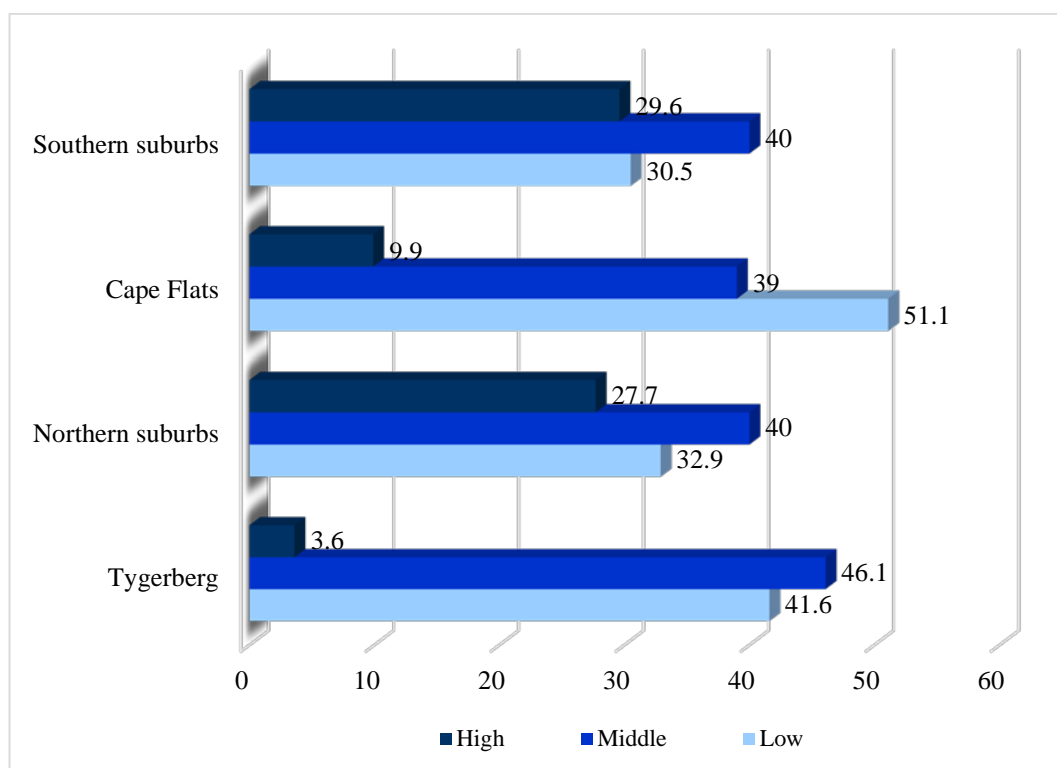
different areas within Cape Town to analyse whether there were specific needs in specific areas or whether most needs were universal within Cape Town.



**Figure 4.3:** Participants in different Cape Town Areas (n = 20)

Figure 4.3 shows the distribution of participants from different areas within Cape Town. These areas included low-, middle- and high-income communities (see Figure 4.4.) Although only 20 participants within the Cape Town area were interviewed, it does give some insight into the social support needs that other family caregivers of persons with physical disabilities might also have within the different socio-economic communities.

This could also potentially indicate a wider spectrum of needs as different communities have different levels of accessibility to certain resources and support services.

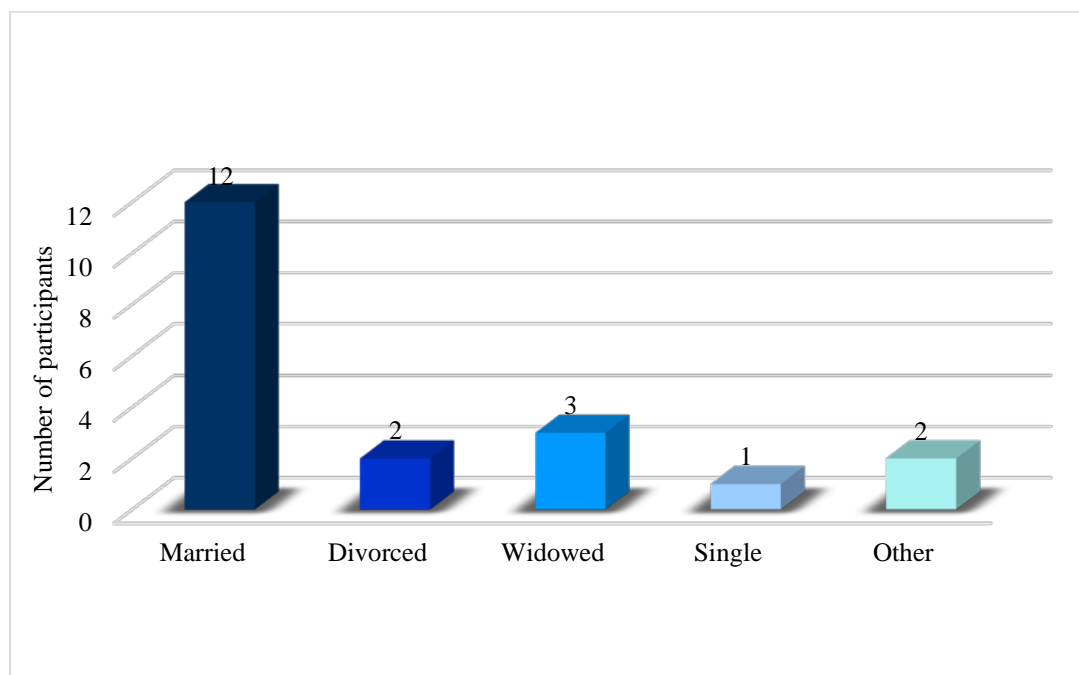


**Figure 4.4:** Socio-economic conditions of areas related to this study (%). Simplified figure created from a 2016 report on Cape Town. (**Source:** Western Cape Government. 2016. *2016 Socio-economic Profile: City of Cape Town*. Cape Town.)

#### 4.3.4 Marital status of participants

Raising a child with a disability could affect the relationship of the caregiver, both positively and negatively. On the negative side, emotional and financial tension may leave a permanent mark within the relationship between parents (Wei and Yu, 2012:100). The parenting responsibilities of parents of children with disabilities can disrupt family and social relationships (Resch et al., 2010:139).

Participants in the research study were asked to state their marital status because having a spouse could potentially assist with the added responsibility of taking care of a person with a physical disability. This could only be confirmed through further studies, but knowing the participants' marital status gave the researcher a better understanding of their family dynamic. The participants' marital status is reflected in Figure 4.5.

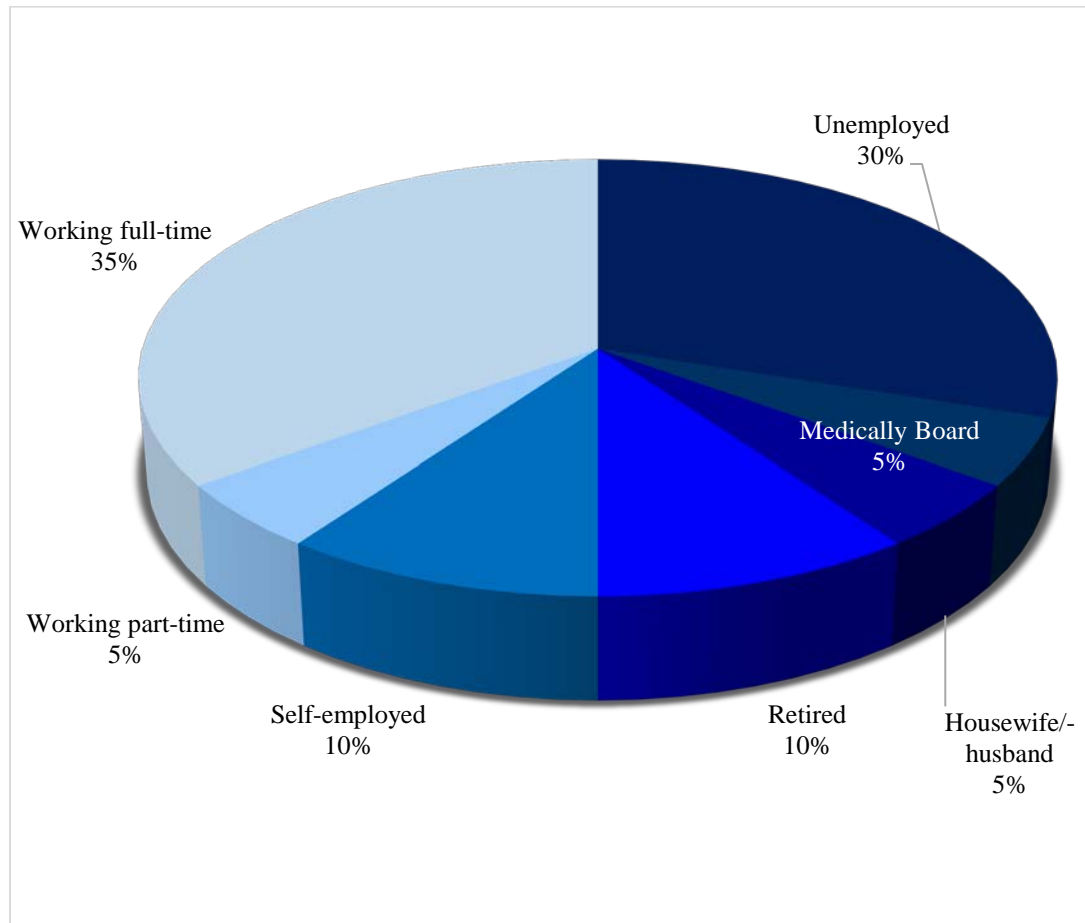


**Figure 4.5:** Participants' marital status (n = 20)

Most of the participants in this study were married, with some of them being the sole carer for the person with a disability. There was also one participant who was engaged and another that did not want to specify. The high prevalence of participants who were still married is in line with a previous study, where some family members reported a greater sense of intimacy, greater family and personal relationships and positive changes in shared family values from taking care of a person with a disability within their family (Elliott et al., 2002:687). Their marital status could indicate the level of social support within the microsystem of Bronfenbrenner's model. The participants' support received and needed with this regard is discussed in Sub-theme 1.1.

#### **4.3.5 Employment status of participants**

Due to the time-consuming responsibility of taking care of a family member with a disability, caregivers either might have to reduce their paid work or refrain from it completely (Hartley et al., 2011:142). According to Wei and Yu (2012:100), the majority of mothers were unable to enter or maintain paid employment, after the birth of their child with a disability(Wei and Yu, 2012:100). The employment status of the participants in the current study is graphically represented in Figure 4.6.



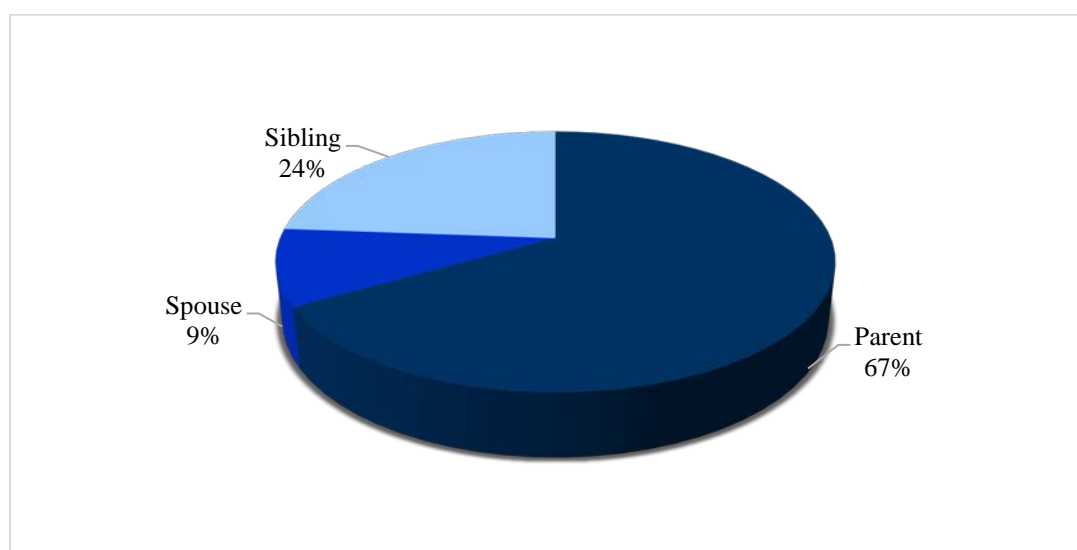
**Figure 4.6:** Participants' employment status (n = 20)

In Figure 4.6 the different employment statuses of the participants are categorised as unemployed, medically boarded, housewife/-husband, retired, self-employed, working part-time and working full-time. Within this categorisation, there was a split between participants who were employed and those who were not. Wei and Yu (2012:100) found that parents of a child with disabilities are more likely to have unstable or no employment, compared to parents who do not have a child with a disability. Even though those who are retired or medically boarded might still get an income, their lack of employment might influence their socio-economic status and their access to resources. Taking care of the child with the disability may last a lifetime instead of the general 18 years, requiring parents to have to set aside money in a trust fund to ensure the child's care when they pass away (Trollope, 2013:9). There is also additional spending on health-care services such as assistive devices, special diets, personal care

and assistance, specialised transportation, heating, laundry services and assistance (Hartley et al., 2011:41). If a family caregiver is unemployed, it could make it difficult to meet these financial needs.

#### 4.3.6 Relationship of participant to person with a physical disability

In Chapter One, it was explained that a family caregiver can be “a family member who, without financial compensation, regularly assists a person in carrying out one or more instrumental activities of daily living” (Collins et al., 2011:1309;Shewchuk and Elliott, 2012:555). This research study had participants who were spouses, siblings and parents to PwDs (see Figure 4.7).



**Figure 4.7:** Relationship of participants to PwDs (n = 24)<sup>1</sup>

Blanes et al. (2007:401) stated that the caregivers of about 90% of persons with chronic disease are their spouses (26.6%), their sisters (23.4%) or their mothers (18.3%). Mothers tend to take on the role of caregivers of the whole family and take on the extra responsibility of taking care of their child with a disability. Reichman et al., (2008:679)

<sup>1</sup>Most of the participants only took care of one person with a physical disability but there were three participants that took care of more than one person with a physical disability. This led to 20 participants (n = 20) being interviewed about their experiences of taking care of 24 different persons with disabilities (n = 24).

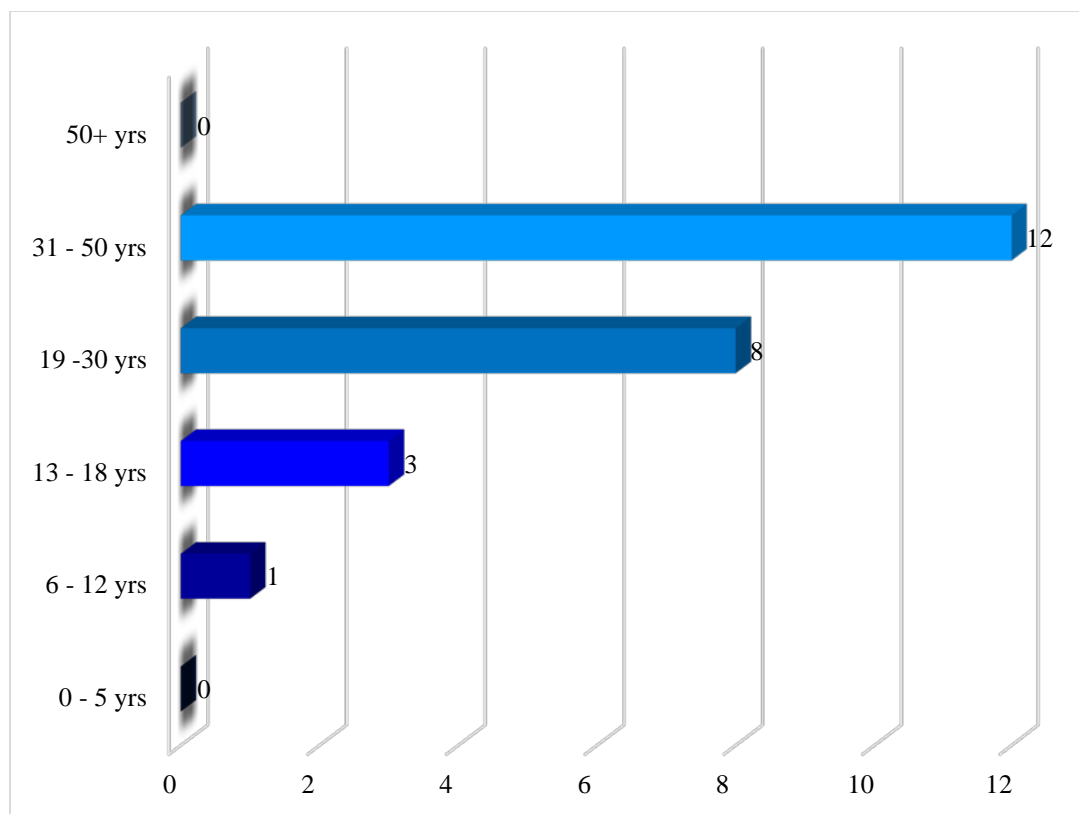
found that living with a person with a disability can have affect the entire family including parents, siblings, and extended family members, both positively and negatively.

In this study, it was mostly parents of persons with physical disabilities that took on the role of the caregiver but there were also some cases of siblings or spouses that took care of the person with a physical disability. The variety in familial relationships towards the PwD that they took care of provided the findings of the study with a more comprehensive view of family caregivers' needs and experiences.

#### **4.3.7 Age group of care dependant(s) of participants**

In a study by Murphy et al. (2007:184), several older caregivers reported that they had developed osteo-arthritis because of years of caregiving. One of the barriers discussed in Chapter Two of this thesis is that as the PwD gets older, it might become more physically demanding to take care of them, therefore the age of the PwD was considered in the researcher's attempt to gain a better understanding of what barriers the participants may be faced with (see Figure 4.8).





**Figure 4.8:** Age group of participants' dependants (n = 24)<sup>2</sup>

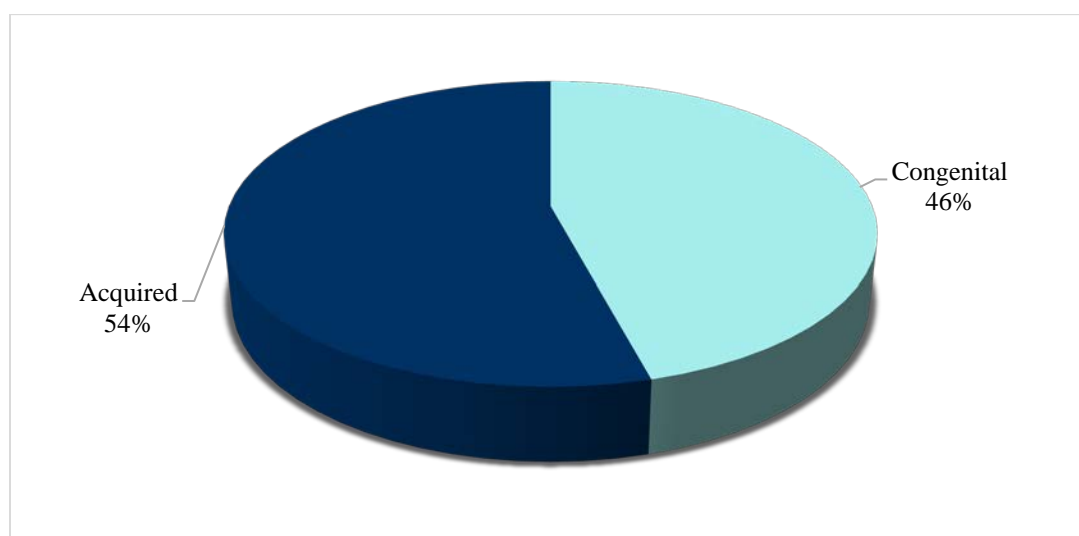
The family members that the participants took care of ranged from 6 to 50 years, with the majority being adults. Most caregivers would face very demanding physical challenges due to their caretaking of adult with physical disabilities. As stated before, in the study by Murphy et al. (2007:184), many parents reported suffering from shoulder pain, which they associated with the regular lifting of the child. In general, caregivers in the current study felt that the physical challenges were more demanding when their child was young but that their own health suffered more when the child got older. Several older caregivers reported that they had developed osteo-arthritis because of years of caregiving.

<sup>2</sup>Most of the participants only took care of one person with a physical disability but there were three participants that took care of more than one person with a physical disability. This led to twenty participants (n = 20) being interviewed about their experiences of taking care of 24 different persons with disabilities (n = 24).

#### 4.3.8 Onset of disability of dependant(s) of participants

The researcher was also interested in looking at whether there was a difference in experiences of family caregivers who were taking care of a person with an acquired disability, compared to those taking care of a person with a congenital disability. A congenital disability is present from birth as a result of either heredity (e.g. SB and CP) or environmental influences. An acquired disability is a disability that occurs after birth and can be as a result of accident or disease (Careerforce, 2015:9; PACER, 2004:1).

Figure 4.9 indicates the onset of disability of the participants' dependants.



**Figure 4.9:** Onset of disability of participants' dependants (n = 24)<sup>3</sup>

The participants in this study took care of both persons with a congenital and an acquired disability, which means that their experiences in both scenarios could be analysed. The difference in their experiences is discussed later in this chapter.

When looking at family caregivers of persons with congenital physical disabilities, it would in many cases be parents who act as family caregivers. They usually have high hopes and dreams for their children. When at birth they then discover that there are

---

<sup>3</sup>Most of the participants only took care of one person with a physical disability but there were three participants that took care of more than one person with a physical disability. This led to 20 participants (n = 20) being interviewed about their experiences of taking care of 24 different persons with disabilities (n = 24).

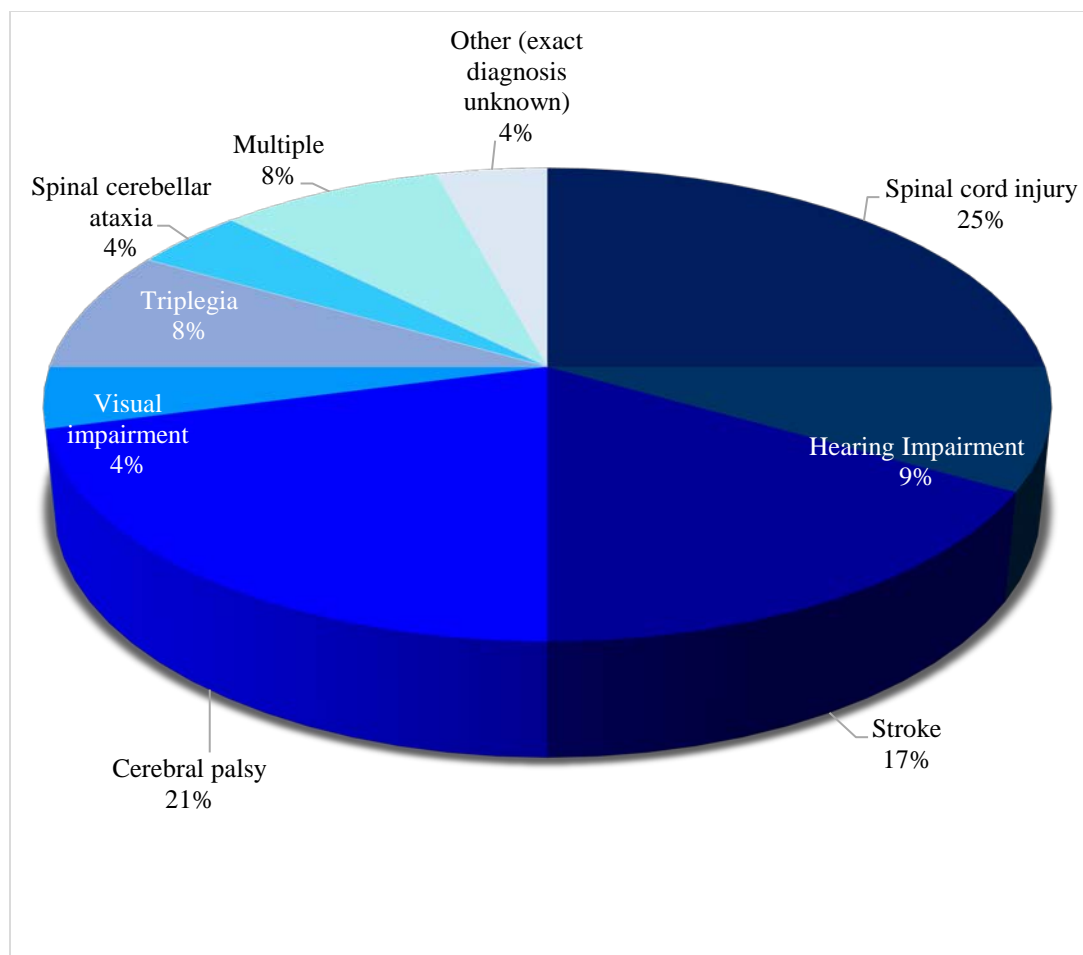
some anomalies with their child, this vision may be suppressed and different emotions may be experienced (Gull and Nizami, 2015:144). Parents also reported at the birth of their baby and during the time spent in hospital that support, both practical and emotional, was needed. However, this support was rarely apparent, especially in terms of a lack of information. Parents reported that they were discharged knowing little about their child's condition or the support that could be offered (Kerr and McIntosh, 2000:319).

With acquired disabilities of family members, the sudden news of a family member who had been in a serious accident which left them disabled leaves most of the family caregivers traumatised and shocked (Broodryk, 2014:43). Kendall and Buys (1998:16) note that the adjustment that must be made after an acquired disability is a recurrent process, characterised by continuous sorrow based in a repetitive pattern of despair and acceptance. Individuals might alternate between 'pre-disability' identity and their new 'disability' identity. This could also be true for the family caregivers.

In both congenital and acquired disability caregiving some adjustment is needed for both the individual and the family caregiver but with an acquired disability there is the added obstacle of comparing the 'pre-disability' life with 'disability' life. For this reason, the researcher wanted to look at both caregiving dynamics.

#### **4.3.9 Type of physical disability of dependant(s) of participants**

Physical disability includes anatomical loss or musculoskeletal, neurological, respiratory or cardiovascular impairment. Physical disabilities can be either congenital or acquired after birth (PACER, 2004:1). In this study, it was important to understand the needs and experiences of family caregivers of persons with various types of physical disabilities. As stated earlier, the dearth of literature on this topic made it necessary for the researcher to consult similar study findings. By interviewing family caregivers of persons with different physical disabilities, the researcher could retrieve information on support needs related to several aspects of caregiving. In Figure 4.10 the types of disabilities of participants' dependants are graphically represented.



**Figure 4.10:** Types of disability of participants' dependants (n = 24)<sup>4</sup>

The participants in this study took care of family members with spinal cord injuries, spinal cerebellar ataxia, triplegia, stroke, hearing impairment, visual impairment, cerebral palsy, multiple (more than one physical disability) and other (where exact diagnosis is unknown by participant but symptoms show physical disability). These types of disabilities are defined in the glossary at the beginning of the thesis.

<sup>4</sup>Most of the participants only took care of one person with a physical disability but there were three participants that took care of more than one person with a physical disability. This led to 20 participants (n = 20) being interviewed about their experiences of taking care of 24 different persons with disabilities (n = 24).

#### 4.4 DATA COLLECTED FROM PARTICIPANTS DURING EMPIRICAL STUDY

The data collected during the empirical study could be classified into different themes, sub-themes and categories as can be seen in Table 4.1 below. This data will be further discussed.

**Table 4.1:** Themes, sub-themes and categories identified in this research study

THEMES	SUB-THEMES	CATEGORIES
<b>Theme 1:</b> Support services used	Sub-theme 1.1: Microsystem	a) Parental subsystem b) Spousal subsystem c) Sibling subsystem
	Sub-theme 1.2: Mesosystem	a) Extended family b) Friends c) Professionals
	Sub-theme 1.3: Exosystem	a) Educational institutions b) Health facilities c) Welfare organisations and other community facilities
	Sub-theme 1.4: Macrosystem	a) South African health-care system b) Education system c) Disability benefits
<b>Theme 2:</b> Support needs	Sub-theme 2.1: Microsystem	
	Sub-theme 2.2: Mesosystem	
	Sub-theme 2.3: Exosystem	a) Lack of schools and training institutions b) Lack of long-term care centres c) Overcrowded health-care facilities d) Lack of public transport e) Lack of recreational groups for PwD f) Lack of information
	Sub-theme 2.4: Macrosystem	a) Policies and legislation b) Disability-friendly employment
<b>Theme 3:</b> General experiences of family caregivers	Sub-theme 3.1: Feelings of grief	
	Sub-theme 3.2: General positive experiences	
	Sub-theme 3.3: General negative experiences	
<b>Theme 4:</b> Barriers experienced by family caregivers	Sub-theme 4.1: Lack of support	a) Community accessibility and safety b) Accessing service c) Personal home accessibility
	Sub-theme 4.2: Caregiver burden issues	a) Physical health issues b) Personal isolation c) Lack of respite services d) Employment issues of caregivers e) Financial issues f) Emotional health issues g) Giving up on own aspirations (caregiver)

<b>Theme 4 (cont.)</b>	Sub-theme 4.3: General issues with PwD	a) Behavioural issues b) Being blamed by PwD
<b>Theme 5:</b> Coping mechanisms of family caregivers	Sub-theme 5.1: Outings	
	Sub-theme 5.2: Recreational activities and hobbies	
	Sub-theme 5.3: Socialising	
	Sub-theme 5.4: Personal time	

#### 4.4.1 Theme 1: Support services used (available to) by family caregivers of persons with physical disabilities in accordance with Bronfenbrenner's model

Bronfenbrenner's model has four different systems, namely the micro-, meso-, exo- and macrosystem. Participants identified different support systems that they already made use of. These support services will be discussed according to Bronfenbrenner's model.

##### 4.4.1.1 Sub-theme 1.1: Microsystem

The microsystem refers to the family caregivers themselves and their closest relationships with other people, for example other family members (Russell, 2003:145). Having a support system at this level seemed to help participants to cope with their situation and enabled them to take better care of the family member with a physical disability.

Most participants indicated that they received support at this level through their parents, spouses, life partners and their children as the main sources of support, whilst four participants indicated that they had no support within this system.

Participant 7: “. . .hier is baie hande in die huis...maar hulle is net nie gemaklik om vir hom te was nie. Ek moet daai waswerk doen. . .” [There are many hands around the house. . .they are not comfortable in washing him. I must wash him.]

Ferrari and Sussman (1987) as well as Seligman and Darling (2007) explain the different subsystems within a family system for support when caring for a person with a disability: the parental subsystem, the spousal subsystem and the sibling subsystem.

a) *Parental subsystem*

The physically disabled child will be dependent on parents to meet their daily needs such as bathing, dressing and doing school work. If the family is functional the support they give can bring some relief to the mother (or father) of the disabled child. The family can stand by each other in dealing with the challenges that are associated with caring for a disabled child, like dependency, social isolation, stigma and continual care (Ferrari and Sussman, 1987; Seligman and Darling, 2007).

Only one participant indicated that his/her parents were their main source of support when caring for a person with a physical disability:

Participant 11: “...ek dink as ek miskien nie hulp gehad het nie (van moeder), dan...sou ek in ’n hoekie gaan sit het...en myself bejammer het.” [I think that maybe if I did not have help (from mother), then I would have gone into a corner and felt sorry for myself.]

b) *Spousal subsystem*

The relationship that the couple have with each other is important as they will need to support each other in raising the child with a disability. They may experience challenges like the financial burden, coping with the long-term grief and depression and facing community and societal reactions (Ferrari and Sussman, 1987; Seligman and Darling, 2007).

Participant 6: (When asked who else besides him takes care of their child with a disability):  
“My wife.”

Participant 14: “. . .was dit nie vir my man nie, dan dink ek nie, sal ge-‘cope’ het...Soos ek altyd vir die mense sê ek is dankbaar vir die Here vir die man wat ek het.”  
[. . .if it wasn’t for my husband, I do not think I would have been able to cope...Like I always say to people, I am thankful to the Lord for the husband I have.]

Participant 15: “. . .You can say teamwork – man and wife. . .”

Participant 19: (Wanneer gevra wie anders na haar broer met fisiese gestremdheid kyk) “Ek sal sê: ‘Net my verloofde’.” [(When asked who else looks after her brother with a physical disability) I would say just my fiancé.]

Figure 4.5 indicated that 12 of the participants were still married. Two of the 12 were taking care of their spouse with a physical disability. Many participants indicated that they use their spouse or life partner as their main source of support when taking care of another family member with a physical disability, indicating that they may share financial burden and other challenges. As stated before, some family members reported a greater sense of intimacy from taking care of a family member with a (physical) disability (Elliott et al., 2002:687).

c) *Sibling subsystem*

This subsystem teaches siblings to show mutual support to the person with a physical disability. Depending on the level of care they can give to the person with a disability, their relationship can be positive or negative (Ferrari and Sussman, 1987; Seligman and Darling, 2007).

There were five participants who took care of their sibling with a physical disability, therefore fulfilling the role as the sibling subsystem. Some of these participants took care of their sibling by choice but in most cases the responsibility was passed onto them when their parents were not able to do the caregiving any longer.

Participant 8: *“Nee, dis my suster. Sy is die een met die gestremdheid.”*

Participant 10: (Wanneer gevra is of hy na sy broer kyk) *“Ja dis korrek.”* [(When asked if participant takes care of his brother) Yes, that is correct.]

Some participants indicated that they inherited their sibling caregiving responsibility when their parents either passed away or were not able to do it themselves any longer. Most of the time, this was not a choice:

Participant 17: *“Die ‘social workers’ van Tygerberg sê vir my ek moet dadelik inkom, hulle wil vir my sien...en hulle vra vir my wie is ek nou rêrig? Ek sê: ‘Ek is sy suster’ . . .Hul vra waar is my ma? Ek sê: ‘My ma is by die huis’. . .Toe sê hulle hy het geroep na (my)... My ma’le is nou nog gesond en my susters en goed. . .Maar hulle sal nie daai. . .vir (my) aflos vandag nie.”* [The social worker



from Tygerberg immediately asked to see me when I got there...and they asked me who I was. I said that I was his sister. They asked me where my mum was and I said that she was at home. Then they said that he had asked for me. My mother and sisters are still healthy but no one will come to relieve me.]

One participant, however, said that she felt that it was the best thing to do to take her brother in:

Participant 19: *“En hulle (ouers) het aanbeweeg na 'n huis van bejaardes... En ons het net gevoel ons voel my broer kan nie na 'n ouetehuis toe gaan nie.”* [And they (parents) moved to the old age home...and we felt that my brother could not go to the old age home.]

Meyer (1993) discusses the cognitive coping strategies of family members with physical disability who are often overlooked, specifically fathers, siblings and grandparents. The author points out that these family members of children with disabilities frequently learn to cope alone, without talking to a peer who has shared a similar experience. This was an important possibility to consider within this study. It is further discussed under Theme 4.

#### 4.4.1.2 Sub-theme 1.2: Mesosystem

The set of links between microsystems is known as the mesosystem (Nash et al., 2005:37). Family caregivers do not only make use of their closest family members for support but also get a form of support from extended family members, friends, professionals and other community members (Edmonds, 2003:757). Caregivers value the support of friends, extended family members and peer organisations (Murphy et al., 2007:184).

##### a) *Extended family*

In a study by Chirwa (2002:216) it was concluded that extended family were seen to be supportive and understanding and served as a source of emotional support for the mothers with children with physical or mental disabilities as they are there to listen to their problems. They are there in time of crisis and provide reassurance. It was found that if the mothers have a good support

system that helps in caring for the disabled child, it is likely that the mother will experience improved mental well-being.

Participant 15: “. . .(when) family came to visit, then they would help. . .”

Only two participants in this study made use of extended family as sources of support. Many of them only used family members as a form of socialising in order to cope with the caregiving role (Theme 5). Most participants indicated that there was a lack of support from their extended family in taking care of their family member with a physical disability. This aspect is discussed under Theme 2.

#### b) *Friends*

Chirwa (2002:216) reported that the second highest assistance for mothers with children with physical or mental disabilities came from friends (42%) whereas 14% of the participants indicated that they became aware of the resources from their communities through their friends.

Participant 8: “*Meeste van die tyd kom my vrinne na my toe, want hulle ken mos nou my omstandighede, my dingese wat ek nou in is so...meeste van die tyd kom hulle na my toe om my aandag miskien nou 'n bietjie af te dinges en so.*” [Most of the time my friends come to me because they know my circumstances...most of the time they come to me to distract me from everything.]

Participants in this study used their friends as a form of support, especially to help them cope with their circumstances. This is discussed further in terms of the socialising coping mechanism of family caregivers of persons with physical disabilities (Sub-theme 5.3).

#### c) *Professionals*

Palisano et al. (2010:90) reported that physiotherapists, occupational therapists, speech therapists, developmental paediatricians, neurologists and orthopaedic surgeons are among the health professionals who provide services to children/youth with CP and other physical disabilities.

The participants made use of various professionals including health professionals from both the private and public health-care systems. Some of the professionals that participants used in taking care of their family member with a physical disability were social workers, physiotherapists, home-based carers, occupational therapists, general practitioners (GPs), speech therapists, audiologists, specialists, educational specialists, class assistants and pastors. These professionals provided support to both the participant and the family member with a physical disability at various levels. All the participants in this study made use of a professional.

Participants sometimes used professionals as a form of emotional support for themselves and even for their family member with a physical disability:

Participant 3: *“Kyk. . .as ek ’n probleem het, gaan ek na my ‘priest’ toe. . . Dan praat ek met hom. Ek praat nie met anders nie. ”* [Look. . .if I have a problem, I go to my priest. . . Then I talk to him. I do not talk to anyone else.]

Participant 7: *“ . . .daar is somtyds dinge wat hy nie met my praat nie, wat hy met haar deel so. . .wat nogal vir my iets goeds is. . .want dan weet ek hy maak nou bietjie oop. . . ”* [ . . .there is sometimes that he (PwD) does not want to talk to me, then he shares with her (peer supporter). . .which is good for me...then I know he’s opening up.]

In most cases, however, professionals were used for service delivery in their specialised field that helped with caring for the persons with a physical disability:

Participant 10: *“Sy (dokter) is baie tegemoetkomend en somtyds dan help sy met die verwysing na die dokters toe, kry die afspraak vroeër eerder as ’n langtydperk vir sekere gespesialiseerde dienste wat benodig word.”* [She (GP) is very accommodating and sometimes she helps with referral to other doctors, gets earlier appointments rather than long periods for certain specialised services.]

Participant 16: *“Hulle is uitstekend. Hulle gebruik nie net die werk se telefoon nie. Hulle gebruik hulle eie telefoon om oproepe te maak.”* [They (social workers) are excellent. They do not only use the work telephone. They also use their own phones to make calls.]

Participant 19: “*Hy’s gereeld by neurologie. . .hump...en hulle is absoluut fantasties. . .uhm, ons het vir (persoon se naam) op fisio ook gehad, maar daar is nie veel wat hulle werklik aan kan doen nie. . .uhm. Ja, ons het. . .uhm, by ’n sielkundige gehad wat hy ook mee gepraat het.*” [He’s at neurology often. . .uhm. . .and they are fantastic. . .uhm, we took him (PwD) to the physio(therapist) but there was nothing they could do for him. . .uhm. . .we had him at a psychologist as well with whom he could talk.]

Formal services such as the use professionals may assist family caregivers (Goldner and Drentea, 2009:501). Being able to work with professionals is one of the indicators of the final stage of grief, acceptance, discussed in Chapter Two (Ross and Deverell, 2010:38) which also coincides with Kübler-Ross’s (1972) final stage of grief.

#### 4.4.1.3 Sub-theme 1.3: Exosystem

The exosystem consists of the settings or systems with which the individual does not necessarily have direct contact, but which may affect their experience of these two systems (Chetkow-Yanoov, 1997:11; Visser, 2007:25). Participants indicated that they made use of social work organisations, disability organisations, public health clinics, public hospitals, rehabilitation centres, tertiary hospitals, private hospitals, churches, special needs schools, mainstream schools with special aids, language centres, after-school training institutions, financial aid trusts, community transport services, horse-riding centres and guide dog services. For most of the participants, where they could access the services, it assisted them with taking care of the family member with a physical disability.

##### a) *Educational institutions*

For children with physical disabilities who are not able to attend mainstream schooling there are also some special care centres, special schools and full-service schools. A total of 1138 children were identified with a disabling condition, giving an estimated prevalence of 1% in the Western sub-district of Cape Town (New Somerset Hospital and Red Cross War Memorial Children’s Hospital). In this study, the carer-to-child ratio in the special care centres

averaged 1:4.4 and in the special schools 1:11.8. The special care centres were, on average, at 82% of capacity. There were significant differences between centres, ranging from 63% capacity to 100% capacity (Redfern, 2013:21).

Participants in this study who made use of specialised schools for their family member with a physical disability, in general, felt that the schools were offering good services and were very helpful:

Participant 4: *“I’m very happy with the school because the boy is doing well at school.”*

Participant 6: *“...when she was at Paarl School, they were excellent. . .”*

Participant 15: *“...the schools did help a lot. . .”*

The number of children with disabilities receiving some form of education has almost doubled over the last 15 years. It has been estimated that there are 464 special schools in South Africa and another 715 ‘full-service’ schools that make provision for children with disabilities. The Department of Basic Education had reached its target of placing more than 240 000 such learners in schools in 2015 (Levy, 2017).

Most of the participants’ family members that they took care of could go to a school that fulfils their special needs up until the age of 18. However, only a few family members could go to a workshop, get employed, or study further, which then led to the participants having to take on the responsibility again of full-time caretaking. This aspect is discussed in Sub-theme 4.2.

*b) Health facilities*

A study on the profile of beneficiaries of social grants found that close to 72% of care dependent households live within five kilometres of their nearest health facility, while 24% live less than one kilometre away; 15% live between five and 10 kilometres away; and 13% live more than 10 kilometres from their nearest health facility (DWCPD and UNICEF, 2012:64).

Although there were some issues with regard to health facilities (that will be discussed later), there were some participants that were satisfied with the services and support they got from health facilities:

Participant 13: “*Kyk. . .partykeer is hulle nogal goed hoor, ek kan nie kla nie. . .As ek sien partykeer dit raak te lank dan...ek ken ook van die verpleegsters daar (daghospitaal) so ek sê vir die ene: ‘Ek sit nou al ’n uur en ’n half hier, almal is nog nie uitgeroep nie.’ Dan maak hulle ’n plan. Dan sê hulle: ‘Ons gaan nou ’n plan maak, jy kan nie so lank sit nie. Jy het ’n kind daar by die huis’.*”  
[Look. . .sometimes they are quite good, I cannot complain. . .If I see sometimes it’s becoming too long. . .I know some of the nurses there (dayhospital) so then I say to the one, ‘I have been sitting for an hour and a half, everyone has not been called out.’ Then they make a plan. Then they say, ‘We are going to make a plan now, you cannot sit so long. You have a child at home.’]

Participants made use of day hospitals, secondary and tertiary hospitals and clinics within the public health sector as well as some private hospitals and private practices of health professionals. Many participants used terms such as “*Tevrede*” [Satisfied] or “*Goed*” [Good] to describe how they felt about the services that they received from the health facilities.

In the Western Cape (WC), a survey was done in 2016 on service delivery in Cape Town (Western Cape Government, 2016:12). It was indicated that Cape Town had two regional hospitals (WC – five), nine district hospitals (WC – 34), 132 primary health-care facilities (WC – 275), 42 community day centres (WC – 58), 17 satellite primary health-care clinics (WC – 72), nine mobile primary health-care clinics (WC – 92) and 81 primary health-care clinics (WC – 208). This indicates quite a widespread of facilities available but a potential gap in mobile clinics which could assist with accessibility.

c) *Welfare organisations and other community facilities*

In South African low-income communities, the NGOs and churches offer a great deal of support to children with disabilities (and their families), such as providing food parcels (Chirwa, 2012:95).

Although most participants made use of health facilities, there were some that made use of other facilities in the community as well (mostly religious institutions):

Participant 13: “*Kyk. . .uhm. . .die ouderling NG Kerk en dominee. . .hy’t vir my gesê: ‘Kyk, dis nie nodig dat jy kerk toe gaan met (seun se naam) nie’, want ek was alleen . . .toe my vrou nog gelewe het toe het ons nog gereeld gegaan met hom en dan sit sy in die konsistorie en ek maar binnekant die kerk, maar toe...nou die laaste drie jaar nou was ons nie in die kerk nie en dan kom diedominee en ouderling en lees uit die Bybel uit.*” [Look. . .uhm. . .the elder of the Dutch Reformed Church and the minister...said to me, ‘It’s not necessary to come to church with (son’s name) because I’m alone. . .when my wife was alive we went regularly and she would sit in the vestry with him (PwD) while I sit in the church but. . .now the last three years we have not been to church and the minister and the elder would come and read the Bible.]

It was found quite often in this study that participants relied heavily on religious institutions for support in terms of respite services, emotional support and sometimes even financial support. Many participants seemed to be very religiously grounded and indicated that the religious institutions helped them cope with their circumstances. ‘Belonging’ to a church community because of their child’s condition is referred to as a spiritual and psychological need by Pelentsov et al. (2015:489).

Welfare organisations were mostly used for workshops for the family member with a physical disability:

Participant 14: “*. . .dit is waarom ek hom in die ‘workshops’ ingesit het. Sodat hy kan...uhm...vriende maak. . .Hy is baie ‘excited’ oor die ‘workshop’, want hy is al in die aande by die huis, en te kom vertel hy het nou dit gedoen, hy het nou dat gedoen en so aan. . .Soos hy is heel ‘excited’ omdat hulle ’n ‘target’ gegee (om produkte te maak) was, nè Nou is hy ‘excited’ om sy ‘target’ te kan doen.*” [...that is why I put him into the workshops. So that he can. . .uhm. . .make friends. . .He is very excited about the workshop because in the evenings he comes and tells me he did this and that. . .So he is very excited because they

gave them a new target (for making products). Now he is very excited to reach the target.]

According to the Cape Town NGO guide (Cape Town, 2017), there are seven organisations that specifically focus on service delivery to persons with physical disabilities and their families.

#### 4.4.1.4 Subtheme 1.4: Macrosystem

Participants made use of many different services within the macrosystem. These include the South African health-care system, the education system and disability benefits. These are all discussed below.

##### a) *South African health-care system*

The South African health-care system is divided into public (government) health services on the one hand, funded through taxes and private health-care services on the other, funded through medical schemes or out-of-pocket payments.

Both these types of health care have their benefits (advantages) and obstacles (disadvantages). Generally, the public health services are free but overcrowded with a limited number of resources for the number of patients they are required to take care of. The private health services are expensive but have more resources available in terms of the number of patients they take care of (Ngubo and Muller, 2015:90-97).

Participants indicated whether they used public, private or a combination of both types of health-care services. Many participants used “*publieke/staatsdienste*” [public/government services], while some used “*privaat dienste*” [private services]. The majority of participants in this study, however, made use of a “*combination of public and private health care*”. This, in most cases meant they used public health-care facilities but also pharmacies and GPs.



In this study, the participants who were interviewed indicated that they utilised both public and private health-care services. Again, the distribution of the different types of health care used provided the research study with a more comprehensive overview of health services for persons with physical disabilities and their families.

As mentioned earlier, within the public health-care sector, participants made use of clinics, day hospitals, secondary hospitals and tertiary hospitals. Within the private sector they made use of private practices of professionals, pharmacies and private hospitals. Some of the expected obstacles of each type of health-care system were experienced; they will be discussed later.

*b) Education system*

As discussed earlier, persons with physical disabilities may have special needs when it comes to the education system. When the child goes to a school, it gives the family caregiver the opportunity to seek employment as the child then has ‘care’ for a certain time.

In 2011, the DBE completed the Guidelines for Responding to Learner Diversity in the Classroom which was introduced during the national orientation programme on the National Curriculum Statement of 2011. The DBE also appointed a ministerial task team to oversee the development of a curriculum for South African Sign Language, Grades R–12 (DWCPD and UNICEF, 2012:60).

Participants did not cite the education as a system specifically but cited the schools and some of the services they received within the education system.

Participant 6: *“I actually think when she was in school she went to a physio and speech therapy.”*

Participant 20: *“So I went to the Department of Education and I met with (person’s name) and he actually gave the school an additional class assistant.”*

Statistics South Africa (2014) investigated the educational level of persons with disabilities and found only about a quarter of persons with physical disabilities, hearing impairments and visual impairments had completed high school and only about 4% to 5% of each group went on to finish higher education.

c) *Disability benefits*

The CDG is awarded in terms of the Social Assistance Act, and is given to poor parents, foster parents or primary caregivers (DWCPD and UNICEF, 2012:56). The South African Social Security Agency (SASSA) administers the distribution of CDGs. To qualify for a grant, a child must be younger than 18 years, not be living in a residential institution, and have a severe disability requiring full time and special care (Redfern, 2013:57).

A 2006 national study on the profile of children in receipt of CDGs found that the most frequently mentioned reasons for receiving this grant were intellectual impairments (26%), physical impairments (23%) and speech, intellectual and emotional impairments (10%). Research suggests that the CDG has a significant and positive impact on children and households that are recipients (DWCPD and UNICEF, 2012:56). In January 2012, SASSA was providing 9803 CDGs in the Western Cape (Redfern, 2013:57).

Depending on the type of the disability the person they took care of was, family caregivers made use of a variety of disability benefits, including guide dogs, class assistants, the CDG as well as tax subsidies. However, there were some obstacles with accessing disability benefits, which will be discussed later in Sub-theme 4.1.

Participant 6: *"I mean my wife is working, because she is working alone and it's difficult for us you know. So now we're busy with SASSA now so now we're trying to get SASSA money too for us. . .she's (PwD) getting a guide dog. . .They're training it by us at the end of the month and it's two weeks training time so she should have it. It's more like a caregiving dog."*

Participants made use of spectacles, wheelchairs and hearing aids where necessary:

Participant 6: *“The wheelchair that she got now is from the school still.”*

Participant 20: *“(PwD) actually has a hearing system. . .And the teacher has a speaker around her neck. It is literally just a speaker system. It is a very expensive system. It cost R40 000.”*

The National Indicator Data Set of the DoH provides information on the provision of new wheelchairs, hearing aids and walking aids (excluding visual aids). Provincial level data (obtained through the district health information system is also not systematically disaggregated by age to allow tracking of provision to children. Assistive devices issued in 2008/09 in KwaZulu-Natal included 1 988 wheelchairs, 1 113 hearing aids, and 1 900 spectacles (DWCPD and UNICEF, 2012:56).

#### **4.4.2 Theme 2: Support needs of family caregivers of persons with physical disabilities in accordance with Bronfenbrenner’s model**

The previous section focused on the support services that the participants were already using in taking care of a PwD. However, most of the participants still had some needs that had not been met yet. Pelentsov et al. (2015:489) conducted a study on the support needs of parents of children who had a rare disease and classified them as social, informational, emotional, practical, physical, spiritual and psychological needs.

Emotional needs could include stress, anxiety, guilt, blame, uncertainty, worry, anger, frustration, powerlessness, shock, denial and fear. Psychological needs include depression and anxiety and stress (Pelentsov et al., 2015:489). These needs are discussed later in terms of the experiences (emotions) that participants felt. Psychological needs can also include coping and self-worth (Pelentsov et al., 2015:489), which are discussed in the section on the coping mechanisms used by participants.

Physical needs refer to health problems associated by parents (caregivers), fatigue and exhaustion, poor sleep, loss of appetite, weight loss, headaches and frequent illness

(Pelentsov et al., 2015:489). Some of these are discussed in this section but also in the section on the barriers that participants faced in caring for a person with a physical disability.

Practical needs could include finances, work and employment, respite and leisure, accessing services and support, childcare and other carers as well as transport. Informational needs could include accessible and relevant information, early and definitive diagnosis, information on the child's illness, resources and services for family and friends and the child's future health needs. Social needs can include isolation and loneliness, family and friends' support, health-care professional partnerships, work-life balance, partner and siblings' relationships and social expectations (Pelentsov et al., 2015:489). Some of these needs will be discussed in terms of Bronfenbrenner's model.

#### 4.4.2.1 Sub-theme 2.1: Microsystem

The emotional and financial tension of raising a child with a disability may leave a permanent mark within the relationship between parents (Wei and Yu, 2012:100).

Although many of the participants received adequate support at the microsystem level, there were some that did not have significant support. Some participants were in relationships before they started taking care of a person with a physical disability (usually in these cases a sibling) but the relationship broke off soon after. Figure 4.5 indicated that two of the participants were divorced.

Participant 17: *"En ek was getroud ook gewees. My man kon nooit reggekom het met hom (broer) nie. En ek het geskei van hom. "*[I was married. My husband could never get along with him (brother). And I divorced him.]

Murphy et al. (2007:184) found that a small percentage (10%) of marriages that formed part of the study had ended in divorce. Some participants just indicated that since they had the extra responsibility of taking care of a person with a physical disability, they never had any form of support.

Participant 14: *"...ek het susters en broers en niemand kom haal hom vir 'n naweek nie. Niemand kom help of 'whatever' nie. Ons het verlede jaar. . . weggegaan met vakansie. . . En ek het vir my suster gevra om hier te kom bly en na hom te kom kyk en ek moet haar betaal*

*het. . .*” [I have sisters and brothers and no one comes to fetch him (brother with disability) for a weekend. No one comes to help or whatever. We went on holiday last year and I asked my sister to stay here to take care of him and I had to pay her.]

The need for parents (or other family caregivers) to get support from other family members is a social need (Pelentsov et al., 2015:489). This could influence their ability to cope with the caregiving role, which will be discussed in Theme 5.

#### 4.4.2.2 Sub-theme 2.2: Mesosystem

Although there are more facilities, health professionals and technological advances than a few decades ago, one thing still seems to remain absent – on-going support to family caregivers on a very regular basis and not just when there is a problem (Collins et al., 2011:1309-1317).

From the empirical study, professional persons within the community were identified as playing a big role in supporting family caregivers of persons with physical disabilities. However, caregiving assistance and on-going support still seemed to be lacking in most cases.

The need to have support with caregiving is in line with Pelentsov et al.’s (2015:489) study where the need for care was classified as a practical need. Many participants indicated that they needed assistance with caregiving in the form of home-based carers or similar professionals:

Participant 2: *“Ek het regtigwaar hulp nodig. Iemand wat hom kan help. Kyk, want soos hy moet oefen . . . My grootste begeerte is dat hy iemand moet kry wat hom net kan help met die oefeninge.”* [I really need help. Someone to help him. See, he needs to exercise. . . My biggest wish is that he will get someone to help him exercise.]

The Health Systems Trust reported that between 2007 and 2011 only about 25% of HPCSA-registered occupational therapists and 17% of physiotherapists were working in the free public sector (DWCPD and UNICEF, 2012:60). This creates a problem with accessibility of health professionals as the bigger portion of the population cannot afford private practitioner fees. Patients that go to public health care might experience long queues because the patient-to-practitioner ratio is bigger in public

health care than private health care. Another support need that was identified was the need for a peer support group among family caregivers of persons with physical disabilities to assist with on-going support that seemed to be lacking for most participants. This could serve as both a social and a practical need as identified by Pelentsov et al. (2015:489).

Participant 15: *“I don’t really have time to go in the week but if they can have more support groups for people with disabled kids . . .”*

Participant 20: *“I also think parent support groups, uhm, are quite useful. For example, I got on this long journey and I’ve got a certain amount of knowledge that I can impart to somebody that is only embarking on a journey. . .parents’ support group at (school name) was managed by the staff. So, one never had a sense of freedom to speak. And there were serious problems at the institution. And I, I could not get up and talk about it because I would just be shut down. I did try.”*

Taanila et al. (2002:82) found that most of the parents noted the significance of having conversations and exchanging experiences with other parents who had a child with a similar disability. Parents of children with disabilities might rely on these peer support groups, especially if they have no or limited other formal support structures. In working with persons with disabilities and their families in the field, the researcher gained first-hand experience of the importance of support provided by such peer support groups.

#### 4.4.2.3 Sub-theme 2.3: Exosystem

In studying the needs of parents of children with cerebral palsy Palisano et al. (2010:89) found that at least 50% of parents expressed the need for information about services their child might receive in the future and services that are presently available. Such services are: information about planning for their child’s future well-being, help in locating community camps, sports, recreational, social and leisure activities, and more personal time.

Within the participants’ communities, there were still some needs that were unmet, mostly in terms of facilities available. These needs can be summarised into lack of schools and training institutions, lack of long-term care centres, overcrowded health-

care facilities, lack of public transport, lack of recreational support groups for PwDs, and lack of information.

a) *Lack of schools and training institutions*

An article on News24.com (Levy, 2017) headlined the lack of schooling for children with disabilities. Levy states that waiting lists for special schools increase every year. Children on those waiting lists are getting too old to attend school as there are age limits for admission to schools. There is also evidence that ‘full-service’ schools lack the basic facilities required to qualify, such as ramps, suitable toilets and support staff.

Often in poor and rural areas little or no provision is made for children with disabilities. Many children with disability are kept at home because there is not enough space to accommodate them or parents cannot afford school fees since special schools have not been declared ‘no fee’ schools. Levy (2017) cites the Director-General of the Department of Basic Education, Mathanzima Mveli, who agreed that the time has come for the department to declare special schools as no fee schools as a matter of priority.

Although most participants could get their family members with a physical disability into a school that served their particular need, remains clear that in most cases mainstream schools still do not cater for persons with physical disabilities. Dingana (2012:145) claims that educators in mainstream schools need to be orientated to teach children with disabilities to encourage inclusive education and overcome the lack of special schools in the Eastern Cape (which is similar to some of the Western Cape areas). The son of one of the participants was left paralysed after an injury and had to leave school because it was inaccessible to him in the wheelchair.

Participant 1: “*Die skool sal eintlik 'n probleem wees. . . ons gaan hom maar inskryf by (TVET kollege).*” [The school will be a problem. . . we are going to register him at (TVET college).]

In her study, Dingana (2012:115-122) found that some caregivers of persons with physical disabilities felt that their family members needed to be trained for skills to gain some independence. However, it seems that there is a lack of opportunities for persons with disabilities to be able to do this, as stated by one of the participants:

Participant 10: “. . . op die oomblik tans hier in Ravensmead-omgewing, is daar baie min geleenthede vir persone wat miskien hul . . . akademiese vlak wil verbeter met hul gestremdhede om in aanmerking te kom en nie met die staatstoelae afhanklik te wees nie.”[. . .at the moment, here in Ravensmead area, there are very few opportunities for persons that maybe want to improve their academic level to become eligible and not to be dependent on social grants.]

A lack of resources and services for families and PwDs is seen by Pelentsov et al. (2015:489) as an informational need. The lack of schooling could influence the employability of the PwD as well as the opportunity for the family caregiver to have to find time to find employment for themselves or just have some respite time;

*b) Lack of long-term care centres*

Taking care of a person with a physical disability, in many cases, means long-term care for as long as the person lives. Many participants stressed that they were worried about the future of their family member if they are no longer there to care for them, because they did not know what would become of the PwD.

Murphy et al. (2007:184) found that family caregivers of PwDs worried about the future, especially in terms of care after they have passed on. Parents recognised their child with physical disability was different which caused them to worry about their future in terms of opportunities for education, employment, financial independency and the ability to live on their own (Antle et al., 2008:191). This seemed to be the case for most participants as well:

Participant 6: “My biggest concern is what happens when we pass on and go, what’s going to happen to her if she lives another 40 years or 20 years after us. . .there’s



*aunties and uncles but she's not going to get the same support like her parents are giving her."*

Participant 18: "*My grootste bekommernis –gaan daar onmiddellik hulp wees vir hom wanneer ons nie meer die dag daar is nie?*" [My biggest worry – is there going to be immediate help for him (PwD) when we are no longer there one day?]

The lack of long-term care seemed to be emphasised not only in availability but also once participants started talking about the struggles they have had in applying to get their family member with a physical disability into the facilities that are available:

Participant 7: "*Ons het al by 'n tehuis aansoek gedoen, maar hulle het soooo 'n lang waglys.*" [We have applied at a care centre but their waiting list is 'soooo' long.]

Participant 19: "*. . .dis nou al oor die drie jaar wat (maatskaplike werker naam) nou soek vir hom vir 'n plekkie . . .*" [It's been three years that (social worker) has been applying for him for a place.]

The lack of long-term care does not only cause uncertainty for the future of the PwD but also involves some financial obstacles (which will be discussed later in more detail) for the family caregiver. It also limits the caregiver's ability to seek employment:

Participant 8: "*Ek sal dit waardeer. . .as ek vir haar in 'n skool kan inkry, maar ons weet nou nie waar nie, maar as daar 'n plek is, wat vir haar met haar ouderdom (29) . . . ek sal dit waardeer, want soos ek sê, dan kan ek gaan werk en weer 'n inkomste verdien vir die huis. . .*" [I would appreciate it...if I could get her into a school but we do not know where but if there is a place that will take her at her age (29), I would appreciate it because as I've said, then I would be able to work and earn an income for the home. . .]

Dingana (2012:117) also found that some family caregivers of persons with physical disabilities felt that if there were a place where they could take their family member during the day they would have time to do other things.

c) *Overcrowded health-care facilities*

Having access to health-care services is a form of practical need as identified by Pelentsov et al. (2015:489). Participants in the current study made use of both public and private health-care facilities but there was a general feeling that in public health-care facilities there were long waiting times and long queues for services or assistive devices:

Participant 1: *“Hulle gee nie om hoe jy is of kan jy heeldag sit of. . .jy moet nou maar net sit. Jy moet ’n afspraak hê by die kliniek voor hul jou vining help.”* [They do not care if you can sit the whole day or how you are. . .you must just sit. You must have an appointment at the clinic to be helped quickly.]

Participant 2: *“Met (die) kliniek. . .Dis lank sit, baie dae sit jy verniet ook. . .baie dae dan sit jy dan het hulle nie eers die pille wat jy moet hê nie, wat hulle moet gee nie. Dan is dit die heeldag daar.”* [With the clinic. . .you have to sit for a long time, many days you sit for nothing as well...many days you sit and then they do not even have the medication that you must get. Then you are there the whole day.]

Participant 14: *“...die aanvraag en die lyne...is so jy kan nie net gaan en afspraak maak en sê: ‘Ek wil vir hom ’n bril maak nie’. . . Dan kom jy daar, dan sê hulle: ‘Kom oor twee maande,’ dan kom jy oor twee maande en dan is die getal klaar vol gevat. Dan gee hulle vir jou weer ’n datum.”* [ . . .the request and queues. . .are so that you cannot just go and make an appointment to say you want spectacles. . .then you get there, then they tell you to come in two months’ time, then you get there in two months, then the number is already full. Then you get another date.]

Participant 17: *“Dit is maar brille wat hy wil hê deur die kliniek en so. Hulle is stadig en so. Hy wag nou al seker twee jaar.”* [It is spectacles that he wants from the clinic. They are slow. He has been waiting for two years.]

Participant 18: *“U weet mos hoe gaan dit by daghospitale. Besig. Jy sit amper ’n hele dag daar. Veral as jy nou vir die eerste keer soontoe gaan. Dan is dit bietjie van ’n wag en so.”* [You know how it goes at day hospitals. Busy. You sit there almost the whole day. Especially if you go there the first time. Then it is a bit of a wait.]

In a statement by the then Western Cape Minister of Health, Mr Theuns Botha, in 2013, it was confirmed that the Western Cape public health-care system was facing various obstacles which led to overcrowded facilities and long waiting periods. In this statement, the minister issued plans to address these obstacles (Botha, 2013).

This statement indicates that the Western Cape DoH was aware of the issue of overcrowded facilities that participants in this study were referring to but since this statement was made in 2013 and the participants still felt that the overcrowded clinics were a problem, there is clearly still some work to be done on this issue.

d) *Lack of public transport systems within communities*

Routine transportation may become difficult with a child or person with a physical disability especially for poor or inner-city families who rely on public transportation (Reichman, 2008:680). The lack of transport is referred to as a practical need by Pelentsov et al. (2015:489).

Many of the family caregivers said that they found it difficult to take their family member for health-care services, especially if they are in wheelchairs because it is difficult to transport the wheelchairs as well. Some participants had their own transport but most relied on public transport or the assistance of community members. Overall, there was a feeling that there is not adequate support in this regard. Although there are some transport services available, participants faced obstacles in accessing them. The availability and cost of these services also presented a problem:

Participant 1: “*Dial-A-Ride. . . hulle sê altyd daar is nie beskikbaar en so nie. So finansieel kan ons nie bekostig om iemand elke dag te vra om hom te vervoer nie.*” [Dial-A-Ride. . . they always say there is nothing available and so on. So financially, we cannot afford to pay someone every day to transport him (PwD).]

Participant 7: “*Die grootste uitdaging is. . . as nou. . . wanneer ons nou moet uitgaan dan moet ons nou 'n spesiale voertuig kry wat vir hom kan akkommodeer. En dan Dial-a-Ride is nie altyd beskikbaar nie en Dial-a-Ride ry nie oral nie. . .*” [The

biggest challenge is. . . when. . .when we go out, we need to get a special car that will accommodate him. And then Dial-A-Ride is not always available and does not drive everywhere.]

Participant 19: “*Daar is nie genoeg vervoerstelsel vir mense met gestremdhede nie. . .*” [There is not enough of a transport system for persons with disabilities. . .]

In Dingana’s (2012:115-122) study in the Eastern Cape, she found that caregivers of people with physical disabilities had needs in terms of transport facilities for people with physical disabilities. There were obstacles for persons with physical disabilities to be able to use public transport. That meant that they had to hire special transport for them. Although Dingana’s study was conducted in the Eastern Cape, participants in this current study had the same struggles with transport. She suggests that role players such as the Department of Transport and the Taxi Association should be approached to be able to address this problem.

e) *Lack of recreational groups for PwDs*

Recreational groups for PwDs form part of services and support which is considered as a practical need by Pelentsov et al. (2015:489).

Family caregivers indicated an overall lack of support that could assist with some respite time for themselves. As discussed earlier on, this support could be in the form of professional care help, long-term care centres or recreational support groups for the PwD. Many family caregivers were concerned that the PwD did not have enough social and recreational stimulation:

Participant 1: “. . .*daar is nie instansies waar hulle by kan gaan om vir hulle besig te hou nie.*” [. . .there are no institutions where they (PwDs) can go to keep themselves busy.]

Participant 6: “*I mean she’s getting old. She doesn’t get much exercise. She sits in her chair the whole time, she watches TV, she goes out to her friends and comes back, then she sits in front of the TV or with her tablet. There’s nothing else that she can do. There’s no place where she can go and be active with other children or other people in like similar situations.*”

Participant 11: “. . .hy wil nie so alleen sit nie. Dit is wat ons bekommernis is. Hy is alleen.” [. . .he does not want to sit alone. That is our worry. He is alone.]

Participant 14: “Hy (PwD) ‘socialise’ glad nie.” [He (PwD) does not socialise at all.]

The need for recreational activities is also emphasised within the Integrated Service Delivery Model, in which it is stated that the Department of Welfare (Department of Social Development) will raise public awareness to facilitate the integration of people with disabilities into all spheres of social life. It further states that community-based support services and facilities will offer the person and his/her family a wide range of opportunities and options to promote independent living and integration into community life and provide sufficient support to the family caregiver(s) (Department of Social Welfare, 1997).

f) *Lack of information*

Kerr and McIntosh (2000:319) reported that parents indicated at the birth of their baby and during the time spent in hospital that support, both practical and emotional, was needed. However, there was a lack of support in terms of information and parents reported that they were discharged knowing little about their child’s condition or the support that could be offered to them.

Research involving families of children with physical disabilities most often expressed the need for information about services (59%) and their child’s condition (43%) (Palisano et al., 2010:86). This coincides with Russell’s (2003:133) finding that parents may have the need for information, advice, support and practical help when taking care of their children.

Very few participants specifically indicated that they needed information, but throughout the interviews the researcher could identify a general need for more information on certain aspects. The specific information needed varied among the different participants but there seemed to be a general sense of lack of information among participants with very little knowledge of resources or other support services that they can access:

Participant 20: *“The first social worker that I have ever met was when he was five years old...I do feel that parents that are our position are being. . . uhm. . . part of a medical aid with private doctor, don't receive the same social. . . uhm. . . worker support like we should. . . I mean, normally when you have a private doctor you don't need the government's financial system. You need the resource and information.”*

Very few caregivers can afford to devote the time and energy necessary to comprehensive education and training before assuming their role as primary caregiver (Elliott and Pezent, 2008:6). This leads to family caregivers having to take on a role for which they might feel inadequately prepared. Dingana (2012:115-122) found that caregivers of persons with physical disabilities also felt they had some problems on which they needed advice. These include advice on assistive devices and available resources.

Research on the effectiveness of the implementation of disability policy in South Africa found that policies are not aligned to programmes of action for implementation (DWCPD and UNICEF, 2012:73). This seems to be true since the White Paper for Social Welfare, South Africa (Department of Social Welfare, 1997) states that community-based support services and facilities would be offered to the PwD and his/her family, and from the participants' experiences it seems that this has not yet happened.

The researcher further suggests that all government departments that deliver services to people with disabilities (and their families) must raise awareness among the general public about the services they offer. This aspect was also identified by Pelentsov et al. (2015:489) as an informational need.

#### 4.4.2.4 Sub-theme 2.4: Macrosystem

Although many of the participants made use of services within the macrosystem, there were two specific support needs identified at this level, namely a lack of knowledge on policies and legislation as well as a lack of employment for PwDs.

a) *Policies and legislation*

Various policies and legislation have been put in place to assist with service delivery to PwDs and their families, namely the Convention on the Rights of Persons with disabilities, the International Classification of Functioning, Disability and Health, the Constitution of the Republic of South Africa, the White Paper on Integrated National Disability Strategy of 2000, the Integrated Service Delivery Model, the Education White Paper 6 and the White Paper for Social Welfare. These were discussed in Chapter Three.

Although there are various policies and legislation in place that emphasises support services for PwDs and their families, most participants indicated that they were not aware of any policies or legislation of this nature. Only two participants (Participants 7 and 10) were aware of these policies and these participants indicated that they became aware of them through their own research and not through any information given to them, as can be seen from the following comments:

Participant 7: “*Ek het die hele ‘White Paper.’*” [I have the whole White Paper.]

Participant 10: “*Ja, ek is bewus van al die beleide. Sekere beleide wat inkom soos die. . . ‘BEE Status’. . . Dit het deurgekom tydens my tyd vir ’n tydperk wat ek geswot het en dis my werk.*” [Yes, I am aware of all the policies. Some policies that come out are like the. . .BEE status. . .It came out during my studies and it is part of my work.]

This could also be seen as an informational need as identified by Pelentsov et al. (2015:489).

b) *Disability-friendly employment*

In the Western Cape, the employment rate of persons aged 15 to 64 years was highest for persons with visual impairments (41.9%) whereas those with hearing impairments were 35.8% and those with physical disabilities only 21.6%. (Statistics South Africa, 2014).

Some participants' family members could study further and were looking for employment that would provide an extra income and reduce the financial strain on the participant. However, participants noted that it is difficult for their family members to find disability-friendly employment and that instead of easing the responsibility on the family caregiver, it would in most cases would even exacerbate the strain on them:

Participant 7: *“As hy moet ’n werk kry, dan moet ek saamgaan as ’n helper en baie plekke neem nie vir jou so in nie...want hulle wil altyd weet wie gaan die persoon betaal wat jou help, want kyk hy moet mos toilet toe geneem word, iemand moet sy sakkie leegmaak, hy kan dit nie self doen nie.”* [If he must get a job, I would have to go with him and many places don't let you in like that...because they always want to know who will pay the person that helps because he must go to the toilet and someone needs to empty his bag, he can't do it himself.]

This state of affairs has an influence on the family's economic opportunities (which will be discussed later) and the caregiver's opportunity to seek employment themselves – another practical need identified by Pelentsov et al. (2015:489).

#### **4.4.3 Theme 3: General experiences of family caregivers of persons with physical disabilities**

Finding out that a person now has to take care of a person with a physical disability could lead to various emotions and experiences – both positive and negative. Most participants indicated that they had quite negative feelings at the beginning but as time went by, they were able to identify some positive experiences as well.

##### **4.4.3.2 Sub-theme 3.1: Feelings of grief**

Ross and Deverell (2010:36) adapted the five stages of grief identified by Kübler-Ross (1972) into nine phases, namely shock/disbelief, relief, denial, bargaining, guilt, depression, anger, anxiety and acceptance. These were in line with some of the experiences that participants had. The experiences participants had included shock, relief, depression, anxiety (feeling overwhelmed) and acceptance. Some of the participants responded as follows:



Participant 1: “*Ek was geskok. . .ek was baie geskok...ek kon amper nie praat nie. Ek het heeltyd net gehuil. . .*” [I was shocked. . .I was very shocked. . .I could barely talk. I cried the whole time.]

Participant 8: “. . .*ek het so bietjie nou en dan gedink en so, hoe gaan ek maak. . .dis nou nog ’n verantwoordelikheid vir my.*” [. . .I thought now and again how I was going to do this, it’s an added responsibility for me.

Participant 12: “. . .*soos toe hy nou die ‘stroke’ kry. . .Toe moes ek weer vir hom in die huis invat. . .Maar ‘at least’ het ek daai moeder gerus dat ek weet, hoef nie te worry hy is op die straat nie.*”[. . .Like when he got the stroke. . .I had to take him back in the home. . . but at least I had that motherly relief of knowing, I do not have to worry about him being on the street.]

Reichman et al. (2008:680) state that feelings of grief or loss may arise from the sudden recognition that the anticipated ‘normal child’ they had waited for nine months is not a reality.

#### 4.4.3.2 Sub-theme 3.2: General positive experiences

Reichman et al. (2008:679) contend that when looking at the positive side of caring for a person with a physical disability, it can broaden horizons, increase family members’ awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions.

Rodakowski et al. (2012:2229) reported in their study that some caregivers felt that caregiving made them feel useful, needed, important, and confident. Family caregivers that formed part of this study did not specify the feelings identified by Rodakowski but identified five main positive experiences they had in taking care of a person with a physical disability: acceptance, relief, motivation, disability awareness and a sense of maturity:

Participant 2: “*Ek was in ’n karongeluk en baiekeer nê as ek so pyn het en daai, dan motiveer hy vir my*”. [I was in a car accident and many times if I have pain, he (PwD) motivates me.]

Participant 3: “*Ek was nie eintlik kwaad nie, maar binne in my hart het ek vir my gesê dis God se wil. God het dit gebestuur. Dis al wat ek geweet het. Ek het nie gehuil nie, ek was nie kwaad nie en ek is tevrede. Dit wat gebeur het. Ek is tevrede.*” [I wasn’t really angry but in

my heart I told myself that this is God's will, God did this. That's all I knew. I did not cry, I wasn't angry and I am satisfied. That's what happened. I am satisfied.]

Participant 20: *"It's made me more compassionate towards people. It's made me more thoughtful. Uhm. . .made me more aware of people with a disability."*

Participants felt that by taking care of their family member with a disability they became more mature; they gained a better sense of disability awareness and acceptance for their situation. There were also cases where the PwD motivated the family caregiver in difficult times. Some of the participants even felt relief because the disability made their family member stop their life of crime (gangsterism and drugs). These experiences and feelings could be identified as psychological needs (Pelentsov et al., 2015:489).

#### 4.4.3.3 Sub-theme 3.3: General negative experiences

Family members may also experience stress, resentment, depression, ambivalence, anger, denial, depression, embarrassment, fear of stigma, grief, guilt, shock and withdrawal (Gull and Nizami, 2015:144; Goldner and Drentea, 2009:499).

Most participants stated that when they found out that they had to take care of a person with a disability, they first had more negative emotions towards the situation. Some of the feelings identified were grief, shock, confusion, worry, depression, disappointment, sadness and the feeling of being overwhelmed:

Participant 7: *"Ek het baie teleurgesteld gevoel, baie hartseer, ja. Ek het baie gehuil, ja. . ."* [I was very disappointed, very sad, yes. I cried a lot, yes. . .]

Participant 19: *"Bekommerd - vir my broer self en sy toekomsplanne, vir my ook en my toekomsplanne. Alles wat jy beplan moet jy vir hom ook in die prentjie hê."* [Worried – for my brother himself and his plans, for myself and my future plans. Everything you plan, you have to include him in the picture.]

Both the positive and the negative experiences and feelings could be identified as emotional or psychological needs (Pelentsov et al., 2015:489) and some of these feelings are in line with the stages of grief as discussed in 4.4.3.1.

#### **4.4.4 Theme 4: Barriers experienced by family caregivers in taking care of persons with physical disabilities**

Despite services being available in communities, participants identified a few distinct barriers that impose on their caregiving of PwDs. These barriers can be categorised as lack of support, general issues with PwDs, and caregiver burden issues.

Reichman et al. (2008:680) points out that some of the barriers in having a child with a disability in the family are related to financial, emotional and family-context issues. With regard to the financial aspect, families may experience difficulty in finding appropriate and affordable child care, out-of-pocket costs of medical care and other services may be significant, and they might have to rely on public support. On the emotional front, families may experience guilt, blame, or reduced self-esteem. In the current study, participants identified certain barriers to their caregiving role. These barriers were categorised into lack of support, caregiver burden issues and general issues with the PwD.

##### **4.4.4.1 Sub-theme 4.1: Lack of support**

Jeong et al. (2015:619) noted in their study that parents raising a child with a disability felt overwhelmed by the challenge and due to lack of service support they rarely learned the skills to cope with it.

Modifying factors of caregiver stress include the characteristics of the caregiver (e.g. age, marital status, coping ability), the characteristics of the recipient (e.g. the degree of disability), the shared history (relationship) between the caregiver and the person being cared for, social factors (e.g. access to social networks and social support), economic factors (e.g. socio-economic status, ability to access formal care, employment), and the cultural context (Parminder, et al., 2005:627).

Participants identified a lack of support as one of the barriers they face when they take care of a PwD. The lack of support was related to respite services, transport, community accessibility and availability of medications.

a) *Community accessibility and safety*

Dingana (2012:143) suggests that municipalities must attend to roads in the rural areas to ensure accessibility for persons with physical disabilities.

Some participants stated that there were some accessibility issues within their community for their family members with physical disabilities:

Participant 5: “. . .our pavements. . .are so uneven, you can’t even push the wheelchair on the pavement, you have to go in the road.”

Participant 15: “The sidewalks need a lot of attention.”

Another issue identified by the participants was the safety of their community, which would not only be an issue for their family member with a physical disability but could be of greater concern, depending on how independent the person is and their ability to defend themselves. This could add to the participants’ feeling more worried about the person they were taking care of and feeling more responsible for them:

Participant 6: “. . .I would not let her (PWD) go on her own because anything can happen.”

Participant 10: “Hier is nou ’n hele paar. . .bende. . .die sypaadjies is baie hoog vir hulle so hulle kan nie hulleself help nie en van die voertuie. . .is baie spoedvrate hier. Die motoriste is spoedvrate. . .” [Here are quite a few that are gangsters. . .the pavements are also high for them (PWDs) and they cannot help themselves and there are many cars...that are speedracers.]

Participant 17: “Hy kon altyd by die hek uitgegaan het. Dan het hy homself met die voete gestoot so om die blok. Maar soos nou. Hy kan dit nie doen nie. Want hier gaan die skote enige tyd af. . .Want ons is omsingel in die gangstery (Wesbank).” [He also could always go out the gate. Then he pushed himself with his feet around the block. But now...He cannot do that. Because shots are fired at any time...because we are surrounded by gangsterism (Wesbank).]

In the report on the profile of Cape Town (Western Cape Government, 2016:23) it was emphasised that the murder rate of 62 per 100 000 people in 2016 within the City of Cape Town remained well above the Western Cape average of 52. This is a concern for everyone living in Cape Town but even

more so for vulnerable groups such as women, children, the elderly and PwDs. The family caregivers' concern about the safety of their family member with a disability was therefore justified.

*b) Accessing services*

In order to improve accessibility, it is important to ensure the availability of services and disabled people's awareness of the services. Access to services could be limited by physical, communication, information and coordination barriers. Physical barriers could exist with regard to the architectural design of health facilities, or medical equipment, or transportation. Barriers to facilities include inaccessible parking areas, uneven access to buildings, poor signage, narrow doorways, internal steps, and inadequate bathroom facilities. Medical equipment is often not accessible to people with disabilities, particularly those with mobility impairments (Hartley et al., 2011:69-70). Again, these barriers would also affect the caregivers of persons with physical disabilities.

Accessing services is considered a practical need, according to Pelentsov et al. (2015:489). These services could be related to facilities or institutions, professionals or equipment or other supplies. Participants in this study indicated that they found it difficult to access the medication for the person with the physical disability they were taking care of, especially when it came to prescription medications:

Participant 12: *“Wat sou gehelp het as hulle, uh, die pille vir hom kan bring. Hulle het ook dit gedoen. Maar dan het dit ook weer gestop. . .Maar nou moet ek iemand kry om dit te gaan haal en so aan.”* [What could have helped is if they brought the medication to him. They did that but then it stopped. . .But now I have to ask someone to get the medication.]

As discussed earlier, transport for persons with disabilities was found to be a definite need in this study. Transport for people with disabilities is often limited, unaffordable, or inaccessible. This also plays a role in the ability of PwDs and their caregivers to access health care, especially when they are located at a distance from health-care facilities (Hartley et al., 2011:69-70).

Participant 4: *“So, if I had to go and fetch his medication, sometimes they’ll say his prescription. . .he is finished. They make six months’ prescription for every patient so I will just. . .I must bring him. . .they will tell. I must bring him. I cannot bring him there because I am not driving in the first place and if I had to take him there, I must hire a bigger taxi that will cost me R100, I don’t have.”*

Participant 13: *“... (omdat) die daghopsitaal nie (pille naam) aanhou nie, nou moet ek die pille by Tygerberg-hospitaal gaan haal. . .”* [ . . .(because) the day hospital does not have the medication, I have to go to Tygerberg hospital]

Some participants indicated difficulty in accessing some health facilities due to their office hours or the travel distance:

Participant 11: *“Die dokter is net tot ses uur oop. . .Soos u self weet, die meeste moet ’n verwysingsbrief hê voor jy hospitaal toe kan gaan.”* [The doctor is only open until six o’ clock. . .As you know, most of the time you must get a referral before you can go to the hospital.]

As discussed earlier, there is a lack of mobile clinics (Western Cape Government, 2016:12). If this matter could be made a priority in Cape Town, it may assist with the accessibility of health services, medications and equipment.

#### c) *Personal home accessibility*

Home modifications are as a practical need (Pelentsov et al., 2015:489). Many participants indicated that their house was not completely accessible for their family member with a physical disability, especially for those in wheelchairs, in terms of space:

Participant 2: *“Hier is nie genoeg ruimte en spasie nie. Hy kan nie eers in die kombuis kom nie. Hy kan nie daardeur gaan nie. Alles is beknop.”* [There is no space here. He (PwD) cannot get into the kitchen. He cannot go through there. Everything is crowded.]

Participant 6: *“So, the passages are narrow, she’s always bumping, I had to paint now, the door frames is chipped with the wheelchair. She’s in an electric wheelchair so she just motors wherever she wants to go.”*

Dingana (2012:115-122) found in her research in Bika Township, Butterworth, in the Eastern Cape, that caregivers of persons with physical disabilities felt that passages in their homes were too small for wheelchairs to be able to turn around and that they needed more accessible houses. She further suggested that municipalities should give preference to people with physical disabilities living in informal settlements when it came to housing allocation.

#### 4.4.4.2 Sub-theme 4.2: Caregiver burden issues

Jeong et al. (2015:619) describe caregiver burden as an umbrella term for the physical, emotional and financial obstacles the caregiver faces when caring for a person with a physical disability.

In Chapter Two it was discussed that family caregivers of persons with physical disabilities may face caregiving burdens. One of the caregiver burden issues that was identified was the physical strain caregiving has on the caregiver's body. The participants also indicated that the special equipment needed in taking care of a PwD put financial strain on them since many of the family caregivers also had to quit their job to take care of the PwD. Some caregivers stated that since having the extra responsibility of caregiving they suffered from insomnia and social isolation.

##### a) *Physical health issues*

Reichman et al. (2008:680) state that having a disabled child and having to be responsible for lifelong caregiving may increase stress and take a toll on the mental and physical health of parents (and other family caregivers). Some of the participants echoed this view:

Participant 4: *"I'm worried about myself because really I've been warned about all these things. This thing is working on me but the only thing that the counsellor said...the last thing they don't want for me is to get a stroke because if I get a stroke, who's going to take care of us."*

Participant 15: *"When she got bigger, I mean obviously, you know, she was gaining weight, it is heavy on our backs."*

Participant 20: *"From the time he was born I have been up every single night. Sometimes two*

*to three times an hour.”*

Murphy et al. (2007:184) found that caregivers tend to rank their own health needs very low as they focus on caring for the person with the disability. Caregivers in this study reported chronic fatigue, sleep deprivation, chronic physical ailments, shoulder pain and low back pain: This is in line with some of the experiences the participants had with regard to their own physical health, and it included back problems, insomnia and general difficulty with regard to the physical strain of taking care of an (adult) family member with a disability. Figure 4.8 shows that most of the participants were taking care of an adult family member with a physical disability.

*b) Personal isolation*

Family caregivers who experience positive (social) interactions when raising a child (or caring for a family member) with special needs have been found to have greater parenting well-being which in turn also had an effect on the person with the disability they were taking care of (Qayyum et al., 2013:132). Most participants indicated that since having the added responsibility of taking care of a person with a physical disability, they were not able to ‘go out’ as much as before, which could put them at risk of feeling complete personal isolation if they did not have other means of support:

Participant 2: *“Ek kan nie meer uitgaan soos ek altyd uitgegaan het nie, want ek is altyd ‘cautious’ nou my kind is by die huis. Ek kan nie vir hom alleen los nie. Ek kan nie lank wegbly nie. . .want ek is baie bekommerd oor hom.”* [I can’t go out anymore because I am cautious now that that my child is at home. I can’t leave him alone. I can’t stay away long. . .because I’m worried about him.]

Participant 13: *Wel, ek het besef ek kan nie meer uitgaan soos ek wil nie. . .uhm. . .my ure is ingekort, ja. . .en toe besef ek sal op iemand moet staatmaak om as ek wil uitgaan, te vra om net na hom te kyk.* [Well, I realised that I can’t go out as I like any longer. . .uhm. . .my hours are curtailed, yes. . .and then I realised that I will have to depend on someone if I want to go out, to ask them just to look after him.]



Isolation and loneliness are considered a social need as well (Pelentsov et al., 2015:489) but fortunately, as discussed in Theme 1, many participants managed to have some form of social interaction through family and friends.

c) *Lack of respite services*

In a study by Murphy et al. (2007:184) parents of persons with disabilities identified several barriers to accessing resources which included lack of time, lack of respite hours, lack of qualified alternative care providers and low prioritisation of the need. Some parents with young children were reluctant to use respite care because they considered it their responsibility to look after their children themselves, and were reluctant to involve other people in caring for their child (Mannan et al., 2011:43). It was also common for caregivers to use respite hours to care for other family members rather than to restore themselves (Murphy et al., 2007:184).

Many participants in the current study felt they did not have the time to breakaway from their caregiving responsibility or to have some time for themselves:

Participant 4: *“It’s difficult. The thing is you don’t have your time. I don’t have ‘my time’. . . I can never just go out and have coffee somewhere. Even if I go somewhere, I must be rushed. . . I must always make sure that I am here. If I’m not here, if I’m at work.”*

Participant 17: (Wanneer gevra word wat nog benodig word) *“As iemand net vir my kan aflos miskien.”* [(When asked what is still needed) If someone could just relieve me maybe.]

Dingana (2012:115-122) found that caregivers of people with physical disabilities felt that they needed time for themselves. Some caregivers in this study wished that there could be extra help, to help relieve them from the strain of caregiving. They wished to have day-care centres, where they could take their grown-up children, which could assist them in having time to do what they wanted to do (as discussed in Sub-theme 2.3). According to the

Integrated Service Delivery Model, the Department of Welfare (known as Department of Social Development) states that community-based support services should provide sufficient support to the family caregiver(s) (Department of Social Welfare, 1997).

d) *Employment issues of caregivers*

Due to the time-consuming responsibility of taking care of a family member with a disability, family caregivers may have to reduce or completely refrain from their paid employment, leading to financial challenges (Hartley et al., 2011:142).

About half of the participants were not employed at all. Some of them were unemployed because of the responsibility they had to take on as caregivers. They could not make any other provisions in taking care of the PwD due to the lack of long-term care, recreational activities/groups or disability-friendly employment as discussed earlier. Some of the participants gave up their job once they had to take on the caregiving role:

Participant 7: “*. . . ek moes my werk opgee om na hom om te sien. Dit was ’n baie groot opoffering, want dit was mos nou ’n inkomste wat wegval . . .*” [I had to give up my job to take care of him. It was a big sacrifice because it was an extra income that fell away.]

Participant 8: “*Ek het gewerk, maar daai was nou in die tyd wat my ma so siek gewees het . . . en nadat sy mos nou oorlede gegaan het, toe moes ek mos nou maar die werk los . . . Ek kan nie nou werk nie, want as ek gaan werk, wie gaan kyk na haar? . . . Ek het by ’n ‘printing’ plek gewerk in Montague Gardens...en nou in hierdie tyd het daar ook baie geleenthede gekom – werkgeleenthede – dan moeteot ek dit net so laat gaan, want ek kan nie . . . al wil ek so graag . . . maar ek kan nie. Ek het nie ’n keuse nie.*” [I worked but that was in the time my mum was ill. . .and then after she died, I had to leave my work. . .I can’t work right now because who will take care of her (PwD)? . . .I worked at a printing company in Montague Gardens. . .and now in this time there were many opportunities in employment that I had to decline . . . even if I wanted to take it. . .but I can’t. I don’t have a choice.]

These findings correspond with those of Collins et al. (2011:1309-1317), namely that many (family) caregivers adjusted their work schedules to meet their caregiving responsibilities. This could lead to financial issues such as a loss of salary and benefits, loss of promotional and training opportunities and a reduction in retirement savings.

e) *Financial issues*

As discussed, a lack of employment for both the caregiver and the PwD could put extra financial strain on the family. When taking care of a person with a physical disability, there is additional spending including assistive devices, special diets or personal care and assistance. The care of a PwD may also last a lifetime and money might have to be put aside in a trust fund to ensure the care of the PwD if the family caregiver passes away (Trollope, 2013:9). This can be seen as a practical need (Pelentsov et al., 2015:489).

Participants indicated several financial issues that they faced such as medical service and equipment expenses, school-related expenses, specialised transport expenses and just general financial struggles, especially if they were the main income provider:

Participant 2: *“Ja, maar dis baie geld. . . Ons het nou een dag...het ons navorsing gedoen oor rystoele en dit is duur. . .die een wat hulle nou het wat kan...waar hy met die rystoel self kan inry. . .daai was amper R24 000.”* [Yes, but it is a lot of money . . .we did some research the other day about wheelchairs. . .and we found that the one that he (PwD) can ride without help. . . that was almost R24 000.]

Participant 4: *“The difference is that I am struggling. I’m struggling financially. . .”*

Participant 8: *“Sy (PwD) was in ’n skool gewees, maar dit was net vir twee maande... Finansiëel kon ons dit nie bymaak nie.”* [She (PwD) was in a school but only for two months. . .financially we could not keep it up.]

Participant 14: *“Sy ‘hearing aid’ is al ’n hele tyd stukkend al. . .en sy ‘hearing aid’ is R50000. Ek het nie R50000 om vir hom (PwD) ’n ander ‘hearing aid’ te laat maak nie.”* [His hearing aid has been broken for a while now. . .and his hearing aid is R50 000. I do not have R50 000 to get him (PwD) another hearing aid.]

For most of the participants in this study there was a definite barrier when it came to the financial issues in taking care of a PwD, especially for those who were not employed. The financial struggles could involve a secondary issue with regard to being able to access certain services. Parents with a low income might not be able to pay for private (special) education, they will need to make use of public medical facilities and public transport, and they will most probably not be able to put money away in a trust fund for the child (Trollope, 2013:9). As discussed in Sub-theme 2.3, there are several obstacles within the public school, health and transport system for persons with physical disabilities.

f) *Emotional health issues*

Emotional health issues could cause the initial reaction that family caregivers may have about their new caregiving role. Emotional health issues could also arise from the long-term effect of caring for a family member with a physical disability, also known as informal care. Informal care is usually seen as an efficient and cost-effective way of caring for people with disabilities, usually carried out by family members such as in this study. This, however, could have adverse consequences for caregivers, including compromised health-related quality of life –for example posttraumatic stress disorder, emotional distress, caregiver burden, depression, and anxiety (Elliott and Pezent, 2008:2; Kress and Herridge, 2012:341).

As discussed earlier in Sub-theme 3.3, some participants had negative experiences and/or emotions when they found out about their new role in caring for a family member with a physical disability. As time went by, however, some could reflect on some positive emotions as well. However, some participants struggled with their own emotional well-being throughout the time, such as dealing with depression:

Participant 20: *“When (PwD) went to (school’s name), I actually had like a uhm... part-time, part-time depression. I actually had a breakdown. And for the first time in my life I had to go onto tranquilisers. And I am not one of those people.”*

Ross and Deverell (2010:36) found that parents' initial reactions to their child's disability are likely to be negative, and similar to those related to grief. Grief is the process whereby a person can separate themselves from someone or something that has been lost. In Sub-theme 3.1. it was discussed that according to Ross and Deverell there are nine phases of grief, when parents find out their child (or other family member) has a disability. These nine phases were adapted from Kübler-Ross's (1972) original five stages of grief.

g) *Giving up on own aspirations (caregiver)*

As mentioned before, Gull and Nizami (2015:144) point out that parents usually have high aspirations and dreams for their children and when they then discover that there are some anomalies with their child, this vision may be suppressed and different emotions may be experienced.

The participants in this study did not focus much on this aspect as they seemed to have accepted their child's condition after the initial shock was over. Some participants (mostly sibling caregivers) spoke about how their caregiving role meant that they had to give up on their own dreams and aspirations and that they still struggled to come to terms with that the situation:

Participant 8: "*Vir my is dit baie seer. . .hoekom. . .ek is nog baie jonk. Ek is maar 26 jaar oud en daar's klomp dinge in die lewe wat ek ook wou bereik, maar op hierdie stadium kan ek nie daarby uitkom nie. . .*" [It hurts a lot. . .because. . .I'm still very young. I am only 26 years old and there are still many things I wanted to achieve but at this point I cannot achieve them.]

Participant 18: "*Dit, dit het vir my gemaak dat ek het 'n verantwoordelikheid vir die res van my lewe. Ek, ek sal nooit regtig doen wat ek wil doen nie.*" [It, put a responsibility on my shoulders for the rest of my life. I, I will never do what I really want to do.]

Having to give up on their own dreams and aspirations could lead to family caregivers feeling 'an anger turned inward', which in turn could lead to their feeling depressed about their circumstances (Ross and Deverell, 2010:37).

#### 4.4.4.3 Sub-theme 4.3: General issues with the person with (physical) disability

Family caregivers of PwDs in this study highlighted that they sometimes have general issues with the PwD such as dealing with PwD emotions and behaviour, managing a healthy lifestyle of the PwD and communicating with the PwD.

##### a) *Behaviour of the person with a (physical) disability*

Murphy et al. (2007:184) found that some caregivers had also been directly injured by their children's impulsive and occasionally violent behaviour. Some participants in this study were worried about the behaviour of their family member with a physical disability, especially with regard to younger family members in the home. Some of the participants' family members acquired their disability through gangsterism or drug abuse and still showed signs of that risky behaviour:

Participant 7: “. . . hulle is soos mos nou ou ‘gangsters’ . . .” [. . . They are old gangsters. . .]

Participant 12: “. . . dit oorgekom het as gevolg van ‘drugs’ en hy was nie ge-‘rehab’ nie. . . Hy raak baie. . . ‘aggressive’. . . die seun het hy al ge‘choke’. . . en hy wou my dogter ook al geslaan het. . . dit maak vir ‘n mens eintlik bang partykeer. [. . . it happened because of the drugs and he was not rehabilitated. . . He gets very . . . aggressive. . . he choked my son already. . . and he wanted to hit my daughter . . . that scares one sometimes.]

In some cases, participants just noted that the PwD portrayed rude behaviour due to their own frustrations:

Participant 3: “Hy’s ‘n ander mens. Hy’s ‘sometimes’ so anders. . . so onbeskoftheid. Hy praat met my nè, maar dis amper hy verskree vir my en ek hou nie daarvan nie.” [He is a different person. He’s sometimes so. . . so. . . rude. He talks to me but it is almost as if he is screaming at me and I do not like that.]

Participant 11: “Want by tye dan verstaan ons nie wat hy sê nie dan is hy geïrriteerd. En hy is ‘n persoon wat baie gou kwaad raak.” [Because at times we do not understand what he is saying and then he gets irritated. And he gets angry quickly.]

In Broodryk's (2014:16) study on the experiences of caregivers of persons with traumatic brain injuries, caregivers reported added caregiver burden due to neurobehavioural changes in the person they had taking care of, including aggression, impulsivity, cognitive problems, personality changes, social problems, forgetfulness, slowness in carrying out tasks, apathy and repetition. This is more or less what was reported in this current study as well. Although the study did not focus on traumatic brain injury survivors specifically, there were cases of brain injury where the participants' family members as a result of a stroke or an accident.

*b) Being blamed by the person with (physical) disability*

Trollope (2013:9) states that one or both parents might experience feelings of guilt because they might feel that they caused the child's disability. However, in this study, some participants (mostly parents of the PwDs) indicated that the PwD blamed them because they felt that if they had been warned about their risky lifestyle they could have prevented their disability:

Participant 18: “. . .daar is tye, baie keer nou nog, hy noem dit somtyds dat dit my skuld is dat hy so iets (motorongeluk) oorgekom het. . .Ek weet nie hoekom hy dit sê nie, maar hy het wel genoem ek kon hom meer gewaarsku het.” [. . .there are times, still now, that he sometimes says that it is my fault that this (car accident) happened to him. . .I don't know why he says that but he did mention that I could have warned him.]

One participant said that their child blamed them for an operation that went wrong:

Participant 16: “Hy het vir my geblameer. Hy het vir my gesê: ‘I told you don't let them do the operation.’” [He blamed me. He said: ‘I told you don't let them do the operation.’]

Dingana (2012:139) found that caregivers of people with physical disabilities who felt appreciated did not only feel the pain of care-giving, but there were also rewards of caregiving. Being blamed by the PwD could affect the family caregiver's feeling of being appreciated and having a sense of self-worth, a

psychological need identified by Pelentsov et al. (2015:489), which could affect their ability to cope with the caregiving role.

#### **4.4.5 Theme 5: Coping mechanisms used by family caregivers in taking care of persons with physical disabilities**

Several coping strategies were identified in a study conducted in Pakistan on individuals who had a child with a severe learning disability with or without additional physical or sensory disabilities. These include sharing care with others in the immediate family, accepting support from the extended family, being proactive in taking control of their child's care, maintaining interests outside the home, avoiding difficult situations by not taking their disabled child to crowded places, changing their ideas about disability, inner conviction in the initial stages of the child's life that they should look after their child without external help, and finally recognising the personal satisfaction they got from taking care of their child, which strengthened their relationship (Croot et al., 2012:1543).

Paster et al. (2009:1341) examined what coping strategies are used by parents of children with and without disabilities. The eight types of coping strategies identified in the study are planful problem solving, seeking social support, confrontive coping, distancing, self-control, escaping avoidance, accepting responsibility, and positive reappraisal.

There are various coping mechanisms that family caregivers of persons with physical disabilities in this study have been using to cope with the added responsibility of caregiving. These coping mechanisms can be categorised into outings, recreational activities, personal time (distancing) and socialising (social support).

##### **4.4.5.1 Sub-theme 5.1: Outings**

Croot et al. (2012:1543) identified being able to maintain interests outside the home as a coping mechanism.



The participants in this study stated that they sometimes take some time to get out of their community. During this time, they will do activities such as shopping, eating out, taking a drive, dancing, taking a train to Kalk Bay or taking short vacations:

Participant 1: *“As sy pa nou hier is dan gaan ek winkels toe of as daar miskien nou ’n partytjie is dan is hier nou iemand, die nader seun, dan gaan ons om die aand te gaan geniet.”* [If his dad is here then I will go to the shops or maybe if there is a party, the other son will be here, then we go out to enjoy the evening.]

Participant 08: *“Ek gaan dans ’n bietjie. . .As die geleentheid daar is, so een keer ’n maand.”* [I go dancing. . .when there is an opportunity, about once a month.]

Participant 13: *“Dinsdae dan kan pensioenarisse nou verniet ry op die trein van nege-uur af. . .dan ry ek tot in Kalkbaai en dan loop ek daar bietjie rond en so op die hawe, kyk bietjie na die see en die visskuite wat so ry en die robbe wat so in die water is. . .Nou daar is ook ’n vis en tjips plek daar waar jy kan gaan eet en ja. Dan koop ek vir my ’n botteltjie ‘cooldrink’ en vir my ’n vis en tjips en so aan.”* [Tuesdays pensioners can travel by train for free after 9 o’clock. . .then I go to Kalk Bay and walk around there in the harbour, look at the sea and watch the boats and the seals in the water...Now there is a fish and chips place where you can eat. Then I buy myself a cooldrink and fish and chips.]

Participant 17: *“Of ‘sometimes’ gaan ek Stellenbosch toe vir ’n dag. Daai gebeur altyd hier by Desember-maande. Dan voel ek, ek het nie lus vir die huis nie. Die plekkie raak vir my te klein. Dan vat ek die kinders, dan gaan ons. . .Dan sal ek my suster laat ogie hou hier so. . .”* [Or sometimes I go to Stellenbosch for the day. That usually happens in December. Then I do not feel like staying at home anymore. The place gets too small. Then I take the kids and then we go. Then I ask my sister to keep an eye out here.]

Murphy et al. (2007:184) found that one of the common methods of relaxation for caregivers of person with disabilities was shopping. This could act as an ‘escape’ from their caregiving role as described by the participants in this study as well.

#### 4.4.5.2 Sub-theme 5.2: Recreational activities and hobbies

Taanila et al. (2002:81) note that the parents in their study thought that their hobbies had helped them to cope with the stressful situation caused by caring for their child.

If it was not possible to go somewhere, participants would do some recreational activities at home such as gardening, watching TV, playing computer games, doing housework or cooking:

Participant 5: *“Like if I feel today that I need to do my gardening or whatever, I go outside; she does her own thing inside.”*

Participant 10: *“... meeste van die tyd is ons maar huislike persone voor die televisie, besig om rugby te kyk. Dis ook deel van ons ontspanning.”* [. . .most of the time we are homely people in front of the television, busy watching rugby. That is also part of our relaxation.]

Participant 13: *“Ek . . . kyk. . . byvoorbeeld nou op televisie...ek hou van die WWE wrestling. . . En ek het soort van 'n 'game' op die rekenaar wat ek speel teen die rekenaar...ek luister radio ook en die musiek om my aandag bietjie af te lei.”* [I . . . watch television. . . I like WWE wrestling. . . and I have a game on the computer that I play against the computer. . . I listen to the radio as well and music to distract me from everything.]

Participant 18: *“Ek sal miskien gaan lê of boek lees. . . As ek klaar is met werk dan sal ek die meeste van die tyd voel ek wil 'n bietjie rus. Ek sal natuurlik saans vir 'n uur of twee by die TV sit en. . . ek doen my eie huiswerk. Ek was, ek stryk, ek maak skoon, ek maak vensters skoon. . .”* [Maybe I will lie down and read. . . if I'm done with my work I always feel I need a bit of rest. I will obviously watch TV in the evening for an hour or two. . . I do my own housework. I wash, iron, clean and wash the windows. . .]

Participant 19: *“So vir my is dit absoluut my diere. . . uhm. . . ek meen dit is terapeuties. En ek doen joga. . . uhm. . . Luister musiek. Ek doen meditasie. . .”* [So for me it is absolutely my animals. . . uhm. . . I mean it is therapeutic. And I do yoga. . . uhm. . . I listen to music. I do meditation. . .]

Taanila et al. (2002:81) emphasise that it is important for parents of persons with physical disabilities to have time for themselves and their hobbies. They found that the parents who kept their hobbies thought that their hobbies had helped them to cope with the stressful situation caused by the child with disability. It seemed that participants in this study also found ways to continue their hobbies.

#### 4.4.5.3 Sub-theme 5.3: Socialising

Some coping mechanisms that caregivers may use are support groups, respite care, psycho-education, social support, and close relationships (Broodryk, 2014:7-8).

Emphasising the importance of a good support system, many participants stated that they relied on visits to and from friends and family and talks with their spouses to help cope with caring for a person with a physical disability.

Participant 3: “*. . . ek gaan net na my suster toe in Mitchell’s Plain. . . Nou as ek by haar is dan praat ek, dan kom alles uit. Net met my suster.*” [. . . I go to my sister in Mitchell’s Plain. . . Now when I am with her, I talk about everything. Just with my sister.]

Participant 5: “*I go now and again to a friend of mine just to have a cup of coffee like half an hour because then my son is at home, you see. . . uhm. . . other than that, I don’t really get a break.*”

Participant 6: “*. . . we normally sit outside and talk about everything. Here over weekends. Then I run to my neighbour and talk nonsense to him but that’s about it. And then now and again my wife goes to her mother or sisters.*”

The need for social interaction is seen by Pelentsov et al. (2015:489) as a social need. In Sub-themes 1.1 and 1.2 the significance of these support systems to the participants in this study was identified.

#### 4.4.5.4 Sub-theme 5.4: Personal time

Murphy et al. (2007:184) found that caregivers of children with disabilities coped with the daily responsibilities by taking 10 to 15-minute breaks, taking mini-naps, or just sometimes ‘having a good cry’.

Some participants indicated that they made use of personal time to rejuvenate and cope. Their personal time consisted of praying, sleeping, reading, exercising or meditating.

Participant 2: “*. . . ek bid. . . of ek gaan slaap. . .*” [. . . I pray. . . or I go to sleep.]

Participant 7: “*Ek gaan gewoonlik bietjie loop lê in die middag, ek loop lees, somtyds dan loop ek net.*”  
[I usually go lie down in the afternoon, I go read, sometimes I just go take a walk.]

In a study by Palisano et al. (2010:89) it was found that 50.8% of parents identified the need to have more personal time. Although some of the participants could find time for themselves to cope with their caregiving role, many indicated that this was still a need (see Themes 3 and 4).

## **4.5 GENERAL OBSERVATIONS ON THE EXPERIENCES OF FAMILY CAREGIVERS OF PERSONS WITH PHYSICAL DISABILITIES FROM THE EMPIRICAL STUDY**

In the empirical study three main observations were made on the experiences of family caregivers of persons with physical disabilities. These are the links between the themes that were identified in this study, the connections with a previous study as well as some main topics identified.

### **4.5.1 The link between the different themes**

During the research study, especially within the empirical study, the researcher learned that although the research study had five different themes, these themes were interlinked with one another in many cases, with a few exceptions. To demonstrate this, two scenarios could be considered in terms of the following main links that were identified:

- the link between support services used, positive experiences and coping mechanisms used by family caregivers of persons with physical disabilities, and
- the link between support needs, negative experiences and barriers experienced by family caregivers of persons with physical disabilities.

#### **4.5.1.1 The link between support services used, positive experiences and coping mechanisms used by family caregivers of persons with physical disabilities.**

The first main link between the themes of the research study was the one between the services used, positive experiences and the coping mechanisms. The researcher realised that many of the participants referred to these three themes interchangeably. To demonstrate these links, a few scenarios are discussed:

##### *Scenario One*

There were many participants who were still married and indicated that they saw their spouse as their main source of support (Sub-theme 1.1) and therefore took time from their caregiving role with them to go on outings (Sub-theme 5.1) to help them cope with their situation and start to accept it (Sub-theme 3.2).

*Scenario Two*

Similar to Scenario One, some participants used friends or extended family members for their support (Sub-theme 1.2) which gave some of the participants the opportunity to either have time for themselves (Sub-theme 5.4), go out (Sub-theme 5.1) or socialise (Sub-theme 5.3), which helped them cope with their role and assist with them having more positive experiences (Sub-theme 3.2).

*Scenario Three*

Some participants' family members with a disability could work or form part of a workshop (Sub-theme 1.3) during the day which meant that they had some time for themselves (Sub-theme 5.4). This also helped them to have positive experiences in their caregiving roles (Sub-theme 3.2).

#### 4.5.1.2 The link between support needs, negative experiences and barriers experienced by family caregivers of persons with physical disabilities

The second main link between the themes of the research study was between the services needed, negative experiences and the barriers experienced by family caregivers. The researcher realised that many of the participants referred to these three themes interchangeably as well. To demonstrate these links, a few scenarios are discussed:

*Scenario One*

In cases where there were no informal support networks (family or friends) for the participants (Sub-themes 2.1 and 2.2), the participant may experience negative feelings such as being overwhelmed or depressed (Sub-theme 3.3), which would be aggravated by feelings of isolation (Sub-theme 4.2), which could also lead to emotional health issues (Sub-theme 4.2).

*Scenario Two*

Where there was either a lack of recreational groups or other services that can assist in taking care of the PwD (Sub-theme 2.3), it led to a lack of respite services (Sub-theme 4.2) and an inability to find time for coping mechanisms such as personal time,

which could also lead to negative experiences such as feeling overwhelmed (Sub-theme 3.3).

#### *Scenario Three*

Where there was either a lack of recreational groups or other services that can assist in taking care of the PwD (Sub-theme 2.3), it led to a lack of employment opportunities for the caregiver (Sub-theme 4.2), which could then also lead to increased financial issues (Sub-theme 4.2). These financial issues could, in turn, increase negative experiences of caregiving (Sub-theme 3.3).

#### *Scenario Four*

In cases where there was a lack of professional support or problems with accessing support services (Sub-theme 4.1), a lack of respite services (Sub-theme 4.2), overcrowded clinics or lack of transport to access services (Sub-theme 2.3), family caregivers were forced to take care of their family member themselves, which in some cases led to physical health issues (Sub-theme 4.2), which could have an effect on their experience (Theme 3) of taking care of their family member with a physical disability.

#### *Scenario Five*

One of the main needs that were identified by participants is not just short-term respite care for their family member with a physical disability but also long-term care (Sub-theme 2.3), especially in terms of the future when the PwD outlives the family caregiver. This created a general sense of worry (Sub-theme 3.3) amongst family caregivers.

#### *Scenario Six*

Many participants seemed to have a lack of information regarding the services available within their communities, which could then lead to different scenarios (such as the ones discussed above).

These are just some of the examples where a link between themes could be identified. Not all participants experienced these links but since it was present for some, it was valuable to take them into consideration.

#### **4.5.2 Connections with a previous study**

The empirical study demonstrated many of the expected outcomes that correlated with previous studies (discussed in Chapters One to Three). However, some other findings also emerged from this study, namely the issue of accessibility in terms of personal home, the community and services.

During her research, the researcher found one specific study conducted by Dingana (2012) for the fulfilment of the requirements for the MSc degree in Medical Sciences, majoring in Rehabilitation. This study was conducted in the Eastern Cape in South Africa but the empirical study findings were very similar to this current research. These connections were the following:

- Financial issues, for example employment (Sub-theme 4.2)
- Accessibility of homes (Sub-theme 4.1)
- A need for transport (Sub-theme 2.3)
- A need for respite care or extra help (Sub-themes 4.1 and 4.2)
- A need for day-care centres (Sub-theme 2.3)
- A need for advice (including information about services/resources available) (Sub-theme 2.3)

The connection between these two studies could suggest that similar studies in other provinces could be motivated to identify whether these needs are prevalent in the whole of South Africa, which could influence future policy and service prioritisation.

#### **4.5.3 Main topics identified**

From the empirical study, two findings could be concluded, namely lack of information as well as a lack of (relief) care for the person with the physical disability (especially in terms of long-term care). Many participants were worried about the future of their

family member with a disability when they are no longer there to take care of them (Sub-theme 2.3).

During the denaturalised transcribing process, the researcher could identify a general gap of support to participants in terms of these two specific needs. As discussed in Sub-theme 2.3, many participants identified a need for relief care and information. These two needs, however, also came up in other themes as one of the primary causes for other needs. Dingana (2012:145) suggests a movement towards community-based rehabilitation to address the needs for persons with physical disabilities and their families.

#### **4.5.4 Identified topics that did not have many previous studies' findings to compare with**

Participants from this study identified certain experiences and barriers that not many other studies that were used as a precedent for this study focused on. These were mostly found in Theme 4 and included caregivers' feelings of giving up on their own dreams (especially in cases where they took care of a sibling), being blamed by the PwD for his/her disability (especially in cases where the parent was the caregiver) and overall difficulty in communicating and understanding the PwD.

## **4.6 CONCLUSION**

The variety in the profile of the participants provided the research study with a comprehensive overview of the social support services used and still needed of family caregivers from different age groups, socio-economic circumstances and in relation to the PwD. There were some universal findings that were present, despite participants having some variables that differed. Many of the support needs, experiences and barriers from previous studies were identified in this study as well (see Chapters Two and Three). This provided a good foundation for recommendations that are presented in Chapter Five.



## **CHAPTER FIVE**

### **CONCLUSION**

#### **5.1 INTRODUCTION**

In the previous chapters the nature of the study, previous research on similar topics and finally, the result from the empirical study of this research study were discussed. These chapters paved the way for this chapter to conclude on future recommendations of this study.

#### **5.2 LESSONS LEARNED FROM THIS STUDY**

Participants in this study seemed to have two main needs that kept resurfacing in discussions: a lack of information and a lack of continuous care for persons with physical disabilities, especially when they are older than school-going age.

Throughout the interviews with participants, it became evident that many participants were not aware of legislation or policies regarding service delivery related to persons with disabilities or their families. Some participants were also not aware of some of the services they could access within their community. Regarding the services they did access, participants stated that they had become aware of these services mostly through their own research or by hearing about them from their peers. They had not necessarily been informed about the services via the institutions themselves, professionals, organisations or government. This could indicate a need for more grassroots advocacy and information sessions within communities.

The second issue that participants in this study frequently identified is the lack of long-term care for their family member with a physical disability. Although there were specialised schools that could be accessed by the participants' family members, the main challenge was encountered when the family member was older than school-going age. The lack of long-term care led to other issues such as worrying about the future of the PwD, limiting the family caregiver in finding employment opportunities which in return could lead to a greater financial strain and putting a strain on the family caregiver's health due to the effect that long-term physical care has on their health.

These two issues led to one main finding – a general lack of support for family caregivers of persons with physical disabilities. The different responses that participants had regarding their experiences and their needs indicated that most felt more could be done by role players such as government and other service providers to support persons with disabilities and their families. This support would include community accessibility, health service/equipment accessibility, transport, information as well as long-term care for persons with physical disabilities.

Some participants indicated that they had no choice but to take care of their family member with a physical disability. Some of their family members acquired a disability through risky behaviour such as substance abuse and gangsterism and now presented a threat to their own safety due to the PwD's aggressive behaviour. This poses the controversial question: Who is then responsible in cases like these to take care of the PwD – the family or government? This leads to a follow-up question: If it is the family's responsibility, should there not be more support for the family who takes care of the PwD?

In the cases involving PwDs who acquired the disability through gangsterism, there were some who became injured more than 20 years ago, but due to their criminal record they still struggled to find employment although they had studied further to improve their qualifications. Participants also indicated that another reason PwDs struggled to find employment is that many companies do not want to risk hiring persons with disabilities due to the risk of more sick leave days. The PwD's inability to find employment also puts strain on the family caregiver.

Generally, participants in this study felt that much more could be done about service delivery, support for and awareness of the needs of persons with disabilities and their families.

### **5.3 RECOMMENDATIONS**

In the empirical study participants identified several needs regarding assistance. As mentioned before, they felt that overall much more could be done in South Africa but

specifically in their area to address the needs of persons with disabilities and their families.

Two of the limitations of this study were the small sample that was used and that no assumptions or generalisation could be made based on these findings. Nonetheless, a few recommendations could be made based on the needs of some specific role players in the areas in which the research took place.

After considering the findings of the empirical study, the lessons learnt from the study and the limitations of the study, several recommendations are subsequently made for future study as well as to address the needs identified in this study. The recommendations are made according to the themes and sub-themes that were identified in Chapter Four. These themes are:

- Support services used
- Support needs
- General experiences of family caregivers
- Barriers experienced by family caregivers
- Coping mechanisms of family caregivers

### **5.3.1 Research method and design**

The research study used a qualitative approach with some elements of a quantitative approach with regard to identifying particulars of the participants. It used a combination of descriptive and exploratory research design. A combination of deductive and inductive reasoning was used in this research study. The data collection was done by means of a semi-structured interview schedule. For this study, the universe of sampling included all the family members of persons with disabilities. The population was family caregivers of persons with disability identified by the Tygerberg APD in the Cape Town area, and the sample was 20 participants. Purposive sampling was used for 19 of the participants whilst one participant identified him/herself through snowball sampling. The study used a denaturalistic approach to transcribing. The variety in participants was a limitation for the detailed analysis, as discussed in Chapter One. However, it could also potentially indicate transferability of the study.

#### 5.3.1.1 Summary

The small sample for this study was a limitation to this study (discussed in Chapter One). The small houses of some of the participants, where the interviews took place, may also have limited their willingness to share. This, and possibly a difficult questionnaire, led to very short answers from some of the participants, which compelled the researcher to make use of denaturalistic transcribing.

#### 5.3.1.2 Recommendations for future studies

- It is suggested that studies be conducted with bigger sample sizes to confirm the transferability of this study's findings.
- A pilot study should be conducted for future studies to identify possible pitfalls in the study before the bulk of the interviews are done.
- In the case of future studies, the researcher should try to minimise denaturalistic transcribing by ensuring the interview conditions allow for maximum effectiveness.

### 5.3.2 Identifying particulars

During the empirical study, the researcher looked at participants' gender, age, living area, marital status and employment status. The researcher also looked at the familial relationship of participant and the PwD. Some identifying particulars of the PwD were also considered, including their age, the onset of their disability and the type of disability.

#### 5.3.2.1 Summary

As noted in Chapter Four, participants in this study had a widespread profile which provided the research study with comprehensive overviews on the research topic. However, Chapter One indicates that this widespread participant profile was also a limitation to the study since it inhibited focus on a specific homogenous sample.

#### 5.3.2.2 Recommendations for future studies

- Based on the limitation of the widespread participant profile, it is suggested that future studies focus on research samples with a specific profile to enable more in-depth research studies.

- It is further suggested that comparative studies be conducted to determine whether universal findings emerge amongst different sample groups.

### **5.3.3 Theme 1: Support services used**

During the research study, the participants were asked about the services (resources) they used in taking care of a person with a physical disability. These services were categorised into the four systems within Bronfenbrenner's ecological model – microsystem (Sub-theme 1.1), mesosystem (Sub-theme 1.2), exosystem (Sub-theme 1.3) and macrosystem (Sub-theme 1.4).

#### **5.3.3.1 Summary**

During the research study, the participants identified the following support services that they used in terms of the four ecological systems:

- Microsystem – parents, spouses and siblings of the PwD.
- Mesosystem – extended family members, friends and professionals such as teachers, doctors and specialists.
- Exosystem – social work organisations, disability organisations, public health clinics, public hospitals, rehabilitation centres, tertiary hospitals, private hospitals, churches, special needs schools, mainstream schools with special aids, language centres, after-school training institutions, financial aid trusts, community transport services, horse-riding centres and guide dog services.
- Macrosystem – South African health-care system (public and private health care), education system and disability benefits.

#### **5.3.3.2 Recommendations for future studies**

- Due to the limitations of the research study topic, it was not possible to do a full analysis of the services that the participants used; therefore, future studies that focus only on the extent and efficiency of the service utilisation would be recommended.
- It is suggested that future studies could also focus on identifying whether other services are used.

- Another recommendation would be to focus on specific areas to determine whether some services are more prevalent in some areas than in others.

### 5.3.4 Theme 2: Support needs

During the research study, the participants were asked about the support needs they still had when taking care of a person with a physical disability. These support needs were categorised into the four systems within Bronfenbrenner's ecological model – microsystem (Sub-theme 2.1), mesosystem (Sub-theme 2.2), exosystem (Sub-theme 2.3) and macrosystem (Sub-theme 2.4.).

#### 5.3.4.1 Summary

During the research study, participants identified the following support needs in terms of the four ecological systems:

- Microsystem – broken relationships with partners.
- Mesosystem –professional support (formal support) and peer support groups.
- Exosystem –schools and training institutions, long-term care centres, health-care facilities that are not overcrowded, public transport, recreational support groups for PwDs, and information.
- Macrosystem – policies and legislation and disability-friendly employment.

#### 5.3.4.2 Recommendations to address support needs

It is not possible to make specific recommendations that would minimise the risk of termination of relationships, which was indicated by some of the participants. However, addressing some of the other support needs may assist in lessening the strain on the relationship through sufficient support to the family caregiver of persons with physical disabilities. Some of the recommendations for addressing the support needs identified by participants are discussed below.

##### *a) Professional support (formal support)*

The DoH could address the lack of health professionals by employing more health professionals. The participants also identified a need for community-oriented primary care that provides basic primary health-care services such as

health promotion, prevention, treatment, rehabilitation and palliation to the community within the community. This could be done through community health workers, home-based carers or making use of the Primary Health Care Re-engineering model.

*b) Peer support groups*

Many participants identified a need for on-going emotional support, not just from professionals, but also from other people in similar conditions who are facing similar challenges. This need could be addressed by the Department of Social Development in partnership with welfare organisations that can provide professional support and establish peer support groups. Some areas indicated that they have these services but many others were not aware of services such as these.

*c) Schools and training institutions*

The lack of education and training opportunities for persons with physical disabilities could be addressed by the Departments of Basic Education and Higher Education by prioritising development in this area.

*d) Health facilities that are not overcrowded*

The DoH could address the overcrowded clinics by prioritising the development of more facilities and employing more health professionals in order to better service delivery and accessibility, especially in the public health sector.

*e) Lack of long-term care centres*

One of the main concerns of participants in this study was what would happen to their family member with a disability once they are not there any longer. This is a major need within the research area with a general lack of long-term care centres. This need could be addressed through a partnership between the DoH and the Department of Social Development.

*f) Recreational support groups for persons with a (physical) disability (day-care centres)*

Participants reported that they needed more assistance in taking care of the PwD to help with the physical toll it has on their health but also to allow them time for themselves or to seek employment and address financial issues. The DoH could assist with caring for the PwD whilst the Department of Social Development in partnership with welfare organisations could assist with workshops or day-care centres for PwDs to give family caregivers the opportunity to seek employment or to have time for themselves.

*g) Transport for persons with a (physical) disability*

Many participants stated that they had difficulty transporting their family member with a physical disability if they did not have transport of their own. This matter could also be prioritised by the Department of Transport who could make use of the assistance (through partnerships) of local traffic departments, taxi associations and private transport agencies such as Uber and Dial-A-Ride.

*h) Information on resources and services available*

Similar to the previous priority area, all service providers to persons with disabilities and their families could raise awareness of their services to the different communities to ensure maximum utilisation of services.

*i) Medical information on caring for persons with a (physical) disability*

The lack of medical information about the PwD could be addressed by the specific health professional that delivers the service or diagnosis whilst the DoH could raise general awareness on medical information of common disability types within the communities.

*j) Educational information for special needs of person with a (physical) disability*

The Department of Basic Education could give information regarding the special education needs for PwD. This could be aimed towards the family



caregivers as well as educators. Special needs education specialists and occupational therapists could provide more in-depth information on a one-on-one basis to the family caregiver of a person with a physical disability, regarding their specific special educational needs.

*k) Information regarding policies and legislation on persons with a (physical) disability and their families*

The participants in this study were generally not aware of policies and legislation on PwDs and their families. It is suggested that parliament could raise awareness on pertinent issues whilst specific departments could raise awareness on policies and legislation regarding their own service delivery.

*l) Disability-friendly employment*

Some participants indicated that although their family member with a physical disability had tertiary qualifications, they struggled to find employment because of their special needs. This need could be addressed by the Department of Labour as well as the local business chambers who could raise awareness on disability-friendly employment and put in place certain policies and resources to support employment for PwDs.

#### 5.3.4.3 Recommendations for future studies

- Due to the lack of previous research on the support needs of family caregivers of persons with physical disabilities, it is recommended that more similar studies be conducted to emphasise these needs.
- It suggested that future seek to determine whether there are any other needs that should be addressed for family caregivers of persons with physical disabilities.
- Future studies should also be done to analyse whether any of the mentioned needs were addressed and whether the significance of the need has decreased or increased.

#### 5.3.5 Theme 3: General experiences of family caregivers

The participants were asked about their experiences (feelings) in taking care of a person with a physical disability. These experiences were categorised into feelings of grief

(Sub-theme 3.1), general positive experiences (Sub-theme 3.2) and general negative experiences (Sub-theme 3.3).

#### 5.3.5.1 Summary

- Feelings of grief – shock, relief, depression, anxiety and acceptance.
- General positive feelings – acceptance, relief, motivation, disability awareness and a sense of maturity.
- General negative feelings – grief, shock, confusion, worry, depression, disappointment, sadness and the feeling overwhelmed.

#### 5.3.5.2 Recommendations for future studies

- Although studies on general positive and negative feelings of family caregivers of persons with physical disabilities would be useful, it is recommended that a specific focus is placed on the stages of grief and the relation each stage has to the feelings experienced by family caregivers.
- It is furthermore recommended that a comparative study be conducted where the effect of differences between congenital and acquired disabilities on the experiences of family caregivers is explored.

### 5.3.6 Theme 4: Barriers experienced by family caregivers

Participants identified certain barriers to their caregiving role. These barriers were categorised into lack of support (Sub-theme 4.1), caregiver burden issues (Sub-theme 4.2) and general issues with the PwD (Sub-theme 4.3).

#### 5.3.6.1 Summary

- Lack of support – community accessibility and safety, accessing services and personal home accessibility.
- Caregiver burden issues – physical health issues, personal isolation, lack of respite care services, employment issues for caregivers, financial issues, emotional health issues and giving up on own aspirations (caregiver).
- General issues with the PwD – and being blamed by the PwD.

#### 5.3.6.2 Recommendations to overcome barriers

It is proposed that some of the barriers identified by participants could be addressed by means of sufficient support networks. Examples of these barriers are personal isolation, emotional health issues, giving up on own aspirations and being blamed by the PwD. Some recommendations to overcome the other barriers are discussed below.

*a) Community accessibility and safety*

Participants from different areas within Cape Town stated that their community was not accessible for their family member with a physical disability due to crime and infrastructural issues. Depending on the issue within the specific community, the local municipality could allocate further tasks to specific role players to address this need.

*b) Accessing services*

Some participants found it difficult to access specialist services or specific medications for their family members with a disability or even to take them to renew their prescription. This need could also be addressed by the DoH who can consider strategies to make these services more accessible within communities, for example by using mobile clinics.

*c) Personal home accessibility*

Although it is not feasible to assist all family caregivers of persons with physical disabilities with the accessibility of their houses, a focus on the accessibility of RDP houses given to these families in lower socio-economic areas could already be a step towards addressing the need. This could be done by the local municipalities who could also prioritise at-risk families such as families with PwDs.

*d) Lack of respite care services*

The improvement of long- and short-term care for persons with disabilities as discussed earlier will also act as a form of respite care for the family caregivers of PwDs.

*e) Employment issues for caregivers*

Here the same idea applies as with the previous barrier: if the long- and short-term care for persons with disabilities discussed earlier is improved, it will give the family caregiver of the PwD the opportunity to access employment.

*f) Financial issues*

Besides seeking employment for the caregiver or PwD that would improve on financial issues, social assistance could also assist with this aspect. Building on the need for information, there some participants indicated that they struggled to access the social grant. The Department of Social Development in partnership with SASSA could cooperate to ensure that the family caregivers of persons with physical disabilities who need financial assistance get access to social grants. SASSA and the Department of Social Development could raise awareness and provide assistance with the application procedure.

*g) Behaviour of person(s) with (physical) disabilities*

As discussed earlier, there were some participants who were caring for a family member who came from a criminal background and who still displayed aggressive behaviour. During the empirical study, the participants emphasised that their safety and that of their other family members (especially children) was of great concern. The need for greater safety could be addressed by the Department of Social Development in partnership with the Department of Justice and Constitutional Development and the Department of Correctional Services where the PwD had a criminal background related to aggressive behaviour. In cases where the PwD had substance abuse problems the Department of Social Development could partner with the DoH to address the potential needs family caregivers may experience in taking care of the PwD.

### 5.3.6.3 Recommendations for future studies

- Due to the lack of previous research on the barriers experienced by family caregivers of persons with physical disabilities, it is recommended that more similar studies be conducted.

- Again, it is suggested that research be conducted to determine whether there are any other barriers that should be addressed for family caregivers of persons with physical disabilities.
- Another recommendation would be to assess whether these barriers were universal within different living areas, age groups and socio-economic statuses.
- Furthermore, it is suggested that future studies be conducted to analyse whether any of the mentioned barriers have been addressed and whether the significance of the barrier has decreased or increased.

### **5.3.7 Theme 5: Coping mechanisms of family caregivers**

There are various coping mechanisms that family caregivers of persons with physical disabilities in this study have been using to cope with the added responsibility of caregiving. These coping mechanisms can be categorised into outings (Sub-theme 5.1), recreational activities (Sub-theme 5.2), personal time (Sub-theme 5.3) and socialising (Sub-theme 5.4).

#### **5.3.7.1 Summary**

- Outings – shopping, eating out, taking a drive, dancing, taking a train to Kalk Bay or taking short vacations.
- Recreational activities and hobbies – gardening, watching TV, playing computer games, doing housework or cooking.
- Socialising – visits to and from friends and family and talks with their spouses.
- Personal time – praying, sleeping, reading, exercising or meditating.

#### **5.3.7.2 Recommendations for future studies**

- Due to the lack of previous research on the coping mechanisms used by family caregivers of persons with physical disabilities, it is recommended that more similar studies be conducted.
- Again, it is suggested that research be conducted that seek to determine whether there are any coping mechanisms used by family caregivers of persons with physical disabilities.

- Another recommendation would be to assess whether these coping mechanisms used by family caregivers of persons with physical disabilities were universal within different living areas, age groups and socio-economic statuses.

### **5.3.8 Final recommendations for future studies**

As stated in Chapter One, this research study could be beneficial in social work especially in terms of service delivery to persons with disabilities and their families. In considering the limitations of the study, one main recommendation for future studies is to have more similar studies which are both descriptive and explorative. These studies should then focus on different variables such as different research areas, different family caregivers, different age groups of family caregivers, different age groups of PwDs, different disabilities, different socio-economic conditions of participants, and the use of public and/or private health care. Once there are enough studies considering the different variables, commonalities between these studies could be assessed, which could emphasise the common needs of family caregivers of persons with physical disabilities. These research outcomes could then potentially be used to raise awareness of the role players involved to aim at addressing the needs of family caregivers of persons with physical disabilities.

## REFERENCES

- Andr n, E. & Grimby, G. 2004. Dependence in daily activities and life satisfaction in adult subjects with cerebral palsy or spina bifida: a follow-up study. *Disability and rehabilitation*. 26(9):528–536.
- Antle, B.J., Mills, W., Steele, C., Kalnins, I. & Rossen, B. 2008. An exploratory study of parents' approaches to health promotion in families of adolescents with physical disabilities. *Child: care, health and development*. 34(2):185–193.
- Arellano, A. & Peralta, F. 2013. Self-determination of young children with intellectual disability: Understanding parents' perspectives. *British Journal of Special Education*. 40(4):175–181.
- Babbie, E. 2007. *The practice of social research*. Eleventh edition. Belmont: Wadsworth
- Ben-Zur, H., Duvdevany, I. & Lury, L. 2005. Associations of social support and hardiness with mental health among mothers of adult children with intellectual disability. *Journal of Intellectual Disability Research*. 49(1):54–62.
- Blanes, L., Carmagnani, M.I.S. & Ferreira, L.M. 2007. Health-related quality of life of primary caregivers of persons with paraplegia. *Spinal Cord*. 45(6):399–403.
- Bless, C., Higson-Smith, C. & Kagee, A. 2006. *Fundamentals in social research methods: An African perspective*. Cape Town: Juta & Co.
- Bogart, K.R. 2014. The role of disability self-concept in adaptation to congenital or acquired disability. *Rehabilitation Psychology*. 59(1):107–115.
- Botha, T. 2013. Western Cape 's health facilities under pressure. 6 September. [Online], Available: [www.gov.za](http://www.gov.za). [Accessed: 10 July 2017].
- Bricout, J.C., Porterfield, S.L., Tracey, C.M. & Howard, M.O. 2004. Linking Models of Disability for Children with Developmental Disabilities. *Journal of Social Work in Disability & Rehabilitation*. 3(4):45–67.
- Bronfenbrenner, U. 1979. *The ecology of human development: Experiments by nature and design*. Cambridge: Harvard University Press.
- Broodryk, M. 2014. *Traumatic brain injury caregivers' experiences: An exploratory study in the Western Cape*. University of Stellenbosch.
- Cantwell, J., Muldoon, O.T. & Gallagher, S. 2014. Social support and mastery influence the association

between stress and poor physical health in parents caring for children with developmental disabilities. *Research in Developmental Disabilities*. 35(9):2215–2223.

Cape Town. Cape Town NGO Guide. Available at: <http://www.capetown.at/ngos/intro.htm>[Accessed: 13 July 2017].

Careerforce. 2015. *Physical disability and support needs: Learning Guide*.

Chetkow-Yanoov, B. 1997. *Social work practice: a systems approach*. Second edition. New York: The Haworth Press.

Chirwa, L.N.C. 2012. *The experiences of mothers caring for their school-going children with physical or mental disabilities in low-income communities: An ecological perspective*. University of Stellenbosch.

Cohen, C. & Napolitano, D. 2007. Adjustment to Disability. *Journal of social work in disability & rehabilitation*. 6(1–2):135–155.

Collins, L.G., Swartz, K., College, J.M. & Jefferson, T. 2011. Caregiver Care. *American Family Physician*. 83(11):1309–1317.

Correa, V.I. 2013. Physical disabilities. [Online]. Available from: [http://ez.sun.ac.za/login?url=http://search.credoreference.com/content/entry/wileyse/physical\\_disabilities/0](http://ez.sun.ac.za/login?url=http://search.credoreference.com/content/entry/wileyse/physical_disabilities/0) [Accessed 1 June 2016].

Croot, E., Grant, G., Mathers, N. & Cooper, C. 2012. Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child. *Disability and rehabilitation*. 34(18):1540–9.

Dawson, V.L., Balloch, S. & Moore, A.P. 2011. Rehabilitation Services for Persons Affected By Stroke in Jordan. *Disability, CBR and Inclusive Development*. 22(1):73–84.

Department of Education. 2007. *Education White Paper 6: Special Needs Education, Building an Inclusive Education and Training System*. South Africa.

Department of Social Development. 2006. *Integrated Service Delivery Model*. South Africa.

Department of Social Welfare. 1997. *White Paper on Social Welfare*. South Africa.

Devereux, P.G., Bullock, C.C., Gibb, Z.G. & Himler, H. 2015. Social-ecological influences on interpersonal support in people with physical disability. *Disability and health journal*. 8(4):564–572.

DeVivo, M. J., & Fine, P. R. 1985. Spinal cord injury: Its shortterm impact on marital status. *Archives of*



*Physical Medicine and Rehabilitation*. 66:501–504.

De Vivo, M.J., Hawkins, L.N., Richards, J.S., Go, B.K. 1995. Outcomes of post-spinal cord injury marriages. *Archives of Physical Medicine and Rehabilitation*. 76:130–138.

De Vos, A.S., Strydom, H., Fouche, C.B., Delport, C.S.L. 2011. *Research at grass roots: for the social sciences and human service professions*. Fourth edition. Cape Town: CredaCommunication.

Dingana, C.J.N. 2012. *What are the needs of people with physical disabilities in the district of butterworth and how accessible are avialable resources to them*. Stellenbosch University.

Donald, D., Lazarus, S. & Lolwana, P. 1997. *Educational psychology in social context: Challenges of development, social issues and special need in Southern Africa*. Cape Town: Oxford University Press.

Dorsett, P. 2010. The Importance of Hope in Coping with Severe Acquired Disability. *Australian Social Work*. 63(1):83–102.

Drisko, J.W. 2013. Standards for Qualitative Studies and Reports. *Qualitative Research in Social Work*. New York: Columbia University Press.

DWCPD and UNICEF. 2012. *Children with Disabilities in South Africa: A Situation Analysis: 2001-2011*.

Edmonds, S.C. 2003. Behind the numbers: Welfare reform from an ecological perspective. *International Journal of Public Administration*. 26(7):753–771.

Elliott, T.R. & Pezent, G.D. 2008. Family caregivers of older persons in rehabilitation. *NeuroRehabilitation*. 23(5):439–446.

Elliott, T.R., Kurylo, M. & Rivera, P. 2002. Positive growth following acquired physical disability. *Handbook of positive psychology*.

Ferrari, I.M. & Sussman, M.B. 1987. *Childhood disability and family system*. New York: The Haworth Press.

Freedman, V.A. 2008. The Importance of Definitions. *Journal of the American Medical Association*. 299(3):332–334.

Given, L.M & Munhall P.L. 2008. *The SAGE encyclopedia of qualitative research methods*. Thousand Oaks: SAGE Publications, Inc.

Goldner, M. & Drentea, P. 2009. Caring for the disabled: Applying different theoretical perspectives to understand racial and ethnic variations among families. *Marriage & Family Review*. 45(5):499–518.

- Grant, J.S., Elliott, T.R., Weaver, M., Glandon, G.L., Raper, J.L. & Giger, J.N. 2006. Social support, social problem-solving abilities, and adjustment of family caregivers of stroke survivors. *Archives of Physical Medicine and Rehabilitation*. 87(3):343–350.
- Gray, D.E. 2006. Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*. 50(12):970–976.
- Greenfield, E.A. 2011. Using Ecological Frameworks to Advance a Field of Research, Practice, and Policy on Aging-in-Place Initiatives. *The Gerontologist*. 52(1):1–12.
- Gretschel, D. 2016. *Levels of community integration achieved by adults with disabilities post discharge from a specialised in-patient rehabilitation unit in the Western Cape*. Stellenbosch University.
- Greyling, E.C. 2008. *Students with disabilities: Experiences of support and barriers to their development*. Stellenbosch University.
- Gull, M. & Nizami, N. 2015. Comparative Study of Hope and Psychological Well-being among the Parents of Physically and Intellectually Disabled Children. *International Journal of Modern Social Sciences*. 4(42):143–152.
- Gupta, V.B., Mehrotra, P. & Mehrotra, N. 2012. Parental Stress in Raising a Child with Disabilities in India. *Disability, CBR & Inclusive Development*. 23(2):41–52.
- Handicap International. *Disability and Development - A practical approach to inclusion in India*. 2009. Available at: [http://www.hiproweb.org/fileadmin/cdroms/Handicap\\_Developpement/www/docs/6.2/6.2.%20H%20Disability%20and%20Development%20-%20practical%20guide%20\(HI%20India\).pdf](http://www.hiproweb.org/fileadmin/cdroms/Handicap_Developpement/www/docs/6.2/6.2.%20H%20Disability%20and%20Development%20-%20practical%20guide%20(HI%20India).pdf) [Accessed: 30 January 2016].
- Harris, K. R. & Graham, S. 2010. *Working with families of young children with special needs: What works for special-needs learners*. First edition. New York: The Guilford Press.
- Hartley, S., Ilagan, V., Madden, R., Officer, A., Posarac, A., Seelman, K., Shakespeare, T., Sipos, S., Swanson, M & Thomas, M. 2011. *World Report on Disability - report.pdf*.
- Malta. [Online], Available: [http://www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf). [Accessed: 30 January 2016].
- Jeong, Y.G., Myong, J.P. & Koo, J.W. 2015. The modifying role of caregiver burden on predictors of quality of life of caregivers of hospitalized chronic stroke patients. *Disability and Health Journal*. 8(4):619–

625.

Kahana, E., Biegel, D.E. & Wykle, M.L. (Eds.). 1994. *Family caregiving across the lifespan*. Thousand Oaks, CA: Sage.

Kendall, E. & Buys, N. 1998. An Integrated Model of Psychosocial Adjustment Following Acquired Disability. *Journal of Rehabilitation*. 64(3):16–20.

Kerr, S.M. & McIntosh, J.B. 2000. Coping when a child has a disability: exploring the impact of parent-to-parent support. *Child: Care, health and development*. 26(4):309–322.

King, G.A., Baldwin, P.J., Currie, M. & Evans, J. 2005. Planning successful transitions from school to adult roles for youth with disabilities. *Children's Health Care*. 34(3):193–216.

Koopman, G. 2003. *An exploratory study of the experiences of people with disabilities in a social development*. Stellenbosch University.

Kress, J.P. & Herridge, M.S. 2012. Medical and Economic Implications of Physical Disability of Survivorship. *Seminars in Respiratory and Critical Care Medicine*. 33(4):339-347.

Kübler-Ross, E. (1972). On death and dying. *The Journal of the American Medical Association*: 221(2):174-179.

Langenhoven, I. & Richmond, K. 2009. *Disability Allsorts: A Directory of Organisations and Resources for people with disabilities in South Africa*. University of South Africa.

Leiter, V. 2004. Parental Activism, Professional Dominance, and Early Childhood Disability . *Disability Studies Quarterly*. 24(2):1–20.

Levy, M. 2017. *Children with disabilities grow old waiting for schools*. Cape Town: News2. 13 July. [Online], Available: <http://www.news24.com/SouthAfrica/News/children-with-disabilities-grow-old-waiting-for-schools-20170713>. [Accessed: 13 July 2017].

Mannan, H., O'Brien, P., McConkey, R., Finlay, F., Lawlor, A. & Harrington, G. 2011. Complexities in the Provision of Respite Care to Family Carers of Persons with Intellectual Disabilities. *Disability, CBR & Inclusive Development*. 22(2):38–54.

Masasa, T.L. 2002. *Cultural beliefs towards disability: their influence on rehabilitation*. Stellenbosch University.

McBurney, D.H. 2001. *Research methods*. London: Wadsworth Thomson Learning

- Meyer, D.J. 1993. *Lessons learned: Cognitive coping strategies of overlooked family members*. Baltimore.
- Migerode, F., Maes, B., Buysse, A. & Brondeel, R. 2012. Quality of Life in Adolescents with a Disability and Their Parents: The Mediating Role of Social Support and Resilience. *Journal of Developmental and Physical Disabilities*. 24(5):487–503.
- Murphy, N.A., Christian, B., Caplin, D.A. & Young, P.C. 2007. The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development*. 33(2):180–187.
- Nacul, L., Moorthie, S., Kapila, M. & Zimmern, R. 2010. Addressing congenital causes of disability. *The Lancet*. 375(9712):374.
- Nash, M., Munford, R. & O'Donoghue, K. 2005. *Social work theories in action*. London: Jessica Kingsley Publishers.
- National Treasury (Republic of South Africa). 2017. *Budget Review 2017*. [Online], Available: [http://www.treasury.gov.za/documents/national budget/2017/review/FullBR.pdf](http://www.treasury.gov.za/documents/national%20budget/2017/review/FullBR.pdf). [Accessed: 11 July 2016]
- NEXUS Database System. National Research Foundation. Available: [www.nexus.nrf.ac.za](http://www.nexus.nrf.ac.za). [Accessed: 11 July 2016]
- Ngubo, T & Muller, N. 2015. *The South African Health Care System: LA*. Pearson Holdings Southern Africa. Cape Town. p.90 – 97.
- Nosek, M.A., Hughes, R.B., Howland, C.A., Young, M.E., Mullen, P.D. & Shelton, M.L. 2004. The meaning of health for women with physical disabilities: A qualitative analysis. *Family and Community Health*. 27(1):6–21.
- Office of the Deputy President. 1997. *Integrated National Disability Strategy White Paper*.
- O'Leary, Z. 2007. Reflexivity. *The Social Science Jargon Buster*. London: SAGE Publications Ltd.
- Oliver, D.G., Serovich, J.M. & Mason, T.L. Constraints and Opportunities with Interview Transcription: Towards Reflection in Qualitative Research, *Social Forces*, 84(2):1273–1289.
- PACER. *Categories of Diverse Disabilities*. 2004. Available at: [www.pacer.org/C3/.../Categories%20of%20Diverse%20Disabilities.pdf](http://www.pacer.org/C3/.../Categories%20of%20Diverse%20Disabilities.pdf) [Accessed: 14 February 2016].
- Palisano, R.J., Almars, N., Chiarello, L.A., Orlin, M.N., Bagley, A. & Maggs, J. 2010. Family needs of parents of children and youth with cerebral palsy. *Child: Care, Health and Development*. 36(1):85–92.
- Parker, L. 2011. *An ecological perspective of adolescents' need for support during pregnancy*. University

of Stellenbosch.

Parminder R., O'Donnell, M., Rosenbaum, P., Brehaut, J., Bin, Z.S.D.W.D.R.M.S. & Wood, E. 2005. The Health and Well-Being of Caregivers of Children With Cerebral Palsy. *Pediatrics*. 115(6):626–636.

Paster, A., Brandwein, D. & Walsh, J. 2009. A comparison of coping strategies used by parents of children with disabilities and parents of children without disabilities. *Research in Developmental Disabilities*. 30(6):1337–1342.

Pelentsov, L.J., Laws, T.A. & Esterman, A.J. 2015. The supportive care needs of parents caring for a child with a rare disease: A scoping review. *Disability and Health Journal*. 8(4):475–491.

Qayyum, A., Lasi, S.Z. & Rafique, G. 2013. Perceptions of Primary Caregivers of Children with Disabilities in two Communities from Sindh and Balochistan, Pakistan. *Disability, CBR & Inclusive Development*. 24(1):130–142.

Redfern, A. 2013. *An analysis of the prevalence of children with disabilities and disabling chronic illnesses in the Western health sub-district of Cape Town, and the services available for them*. University of Cape Town.

Reichman, N.E., Corman, H. & Noonan, K. 2008. Impact of child disability on the family. *Maternal and Child Health Journal*. 12(6):679–683.

Resch, J.A., Mireles, G., Benz, M.R., Grenwelge, C., Peterson, R. & Zhang, D. 2010. Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation psychology*. 55(2):139–50.

Rodakowski, J., Skidmore, E.R., Rogers, J.C. & Schulz, R. 2012. Role of social support in predicting caregiver burden. *Archives of Physical Medicine and Rehabilitation*. 93(12):2229–2236.

Rosenbaum, P. & Stewart, D. 2004. The World Health Organization International Classification of Functioning, Disability, and Health: A Model to Guide Clinical Thinking, Practice and Research in the Field of Cerebral Palsy. *Seminars in Paediatric Neurology*. 11(1):5-10.

Ross, E. & Deverell, A. 2010. *Health, illness and disability: Psychosocial approaches*. Second edition. Van Schaik Publishers.

RSA (South African) Government. 2016. *Disability Rights Awareness Month 2016; Tax and Disability*.

Rubin, A. & Babbie, E. R. 2005. *Research methods for social work*. Fifth edition. Australia: Thomson Brooks/Cole.

- Russell, F. 2003. The expectations of parents of disabled children. *British Journal of Special Education*. 30(3):144–149.
- Scileppi, J. A., Teed, E. L. & Torres, R. D. 2000. *Community psychology: A common sense approach to mental health*. University of Stellenbosch.
- Seligman, M & Darling, R.B. 2007. *Ordinary families, special children: a system approach to child disability*. Third edition. New York: The Guilford Press.
- Shanbhag, D.N. & Krishanmurthy, A. 2012. Mental Health and Quality of Life of Caregivers of Individuals with Cerebral Palsy in a Community Based Rehabilitation Programme in Rural Karnataka. *Disability, CBR & Inclusive Development*. 22(3):29–38.
- Shewchuk, R. & Elliott, T.R. 2012. Family Caregiving in Chronic Disease and Disability. *Handbook of Rehabilitation Psychology*. 553–563.
- Simplican, S.C., Leader, G., Kosciulek, J. & Leahy, M. 2015. Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*. 38:18–29.
- South African Revenue Service. 2012. *List of Qualifying Physical Impairment or Disability: Section 18 of the Income Tax Act of 1962*.
- South African Revenue Service. 2016. *Income Tax Guide on the Determination of Medical Tax Credits and Allowances*.
- Statistics South Africa. 2005. *Prevalence of disability in South Africa*. [Online], Available: <http://www.statssa.gov.za/publications> [Accessed: 14 February 2016].
- Statistics South Africa. *General Household Survey*. 2013. [Referenced in Redfern (2013)].
- Statistics South Africa. 2014. *Profile of persons with disability in South Africa*. [Online], Available: <http://www.statssa.gov.za/publications/Report-03-01-59/Report-03-01-592011.pdf>. [Accessed: 14 February 2016].
- Taanila, A., Syrjälä, L., Kokkonen, J. & Järvelin, M. 2002. Coping of parents with physically and / or intellectually disabled children. *Child: Care, Health & Development*. 28(1):73–86.
- Trollope, A.M. 2013. *The impact of socio-economic factors on raising a child with mental disability in the North West of Pretoria*. University of Pretoria.
- UNICEF. 2013. The state of the world's children. *Children with Disabilities*.

- Vermaak, C. 2016. *Bridging the gap from inpatient rehabilitation to sustainable health and wellness in spinal cord injured individuals*. University of Stellenbosch.
- Visser, M. 2007. *Contextualising community psychology in South Africa*. Pretoria: Van Schaik Publishers.
- Wait, J., Meyer, J., Loxton, H. 2005. *Menslike Ontwikkeling: 'n Psigososiale Perspektief*. Parow Oos: Ebony Books.
- Wei, X. & Yu, J.W. 2012. The concurrent and longitudinal effects of child disability types and health on family experiences. *Maternal and Child Health Journal*. 16(1):100–108.
- Western Cape Government. 2016. *2016 Socio-economic Profile: City of Cape Town*. Cape Town.
- WHO. 2001. *The International Classification of Functioning, Disability and Health*. World Health Organization.
- Xu, Y. & Filler, J. 2008. Facilitating Family Involvement and Support for Inclusive Education. *The School Community Journal*. 18(2):53–72.

## ANNEXURE A REC Approval Notice



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

---

### Approval Notice

#### Stipulated documents/requirements

11-Nov-2016

Muller-Kluits, Noreth N

Ethics Reference #: SU-HSD-003300

Title: Social Support needs of family caregivers of persons with physical disabilities

Dear Mrs Noreth Muller-Kluits,

Your Stipulated documents/requirements received on 19-Sep-2016, was reviewed and accepted.

Please note the following information about your approved research proposal:

Proposal Approval Period: 25-Aug-2016 - 24-Aug-2017

Please take note of the general Investigator Responsibilities attached to this letter.

If the research deviates significantly from the undertaking that was made in the original application for research ethics clearance to the REC and/or alters the risk/benefit profile of the study, the researcher must undertake to notify the REC of these changes.

Please remember to use your proposal number (SU-HSD-003300) on any documents or correspondence with the REC concerning your research proposal.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at .

Sincerely,

Clarissa Graham  
REC Coordinator

Research Ethics Committee: Human Research (Humanities)

*National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.*

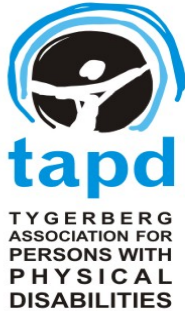
*The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.*



## ANNEXURE B

### Consent Form for Research through Tygerberg APD

Enquiries: Mrs. C. Gerber



19/07/2016

Who it may concern

### CONSENT FORM

PO Box 563  
Goodwood  
7459

C/o 100 Voortrekker Rd  
& Alice Street  
Goodwood  
7460

Tel: +27 021 592 4173  
Fax: +27 021 592 4371  
tygerbergapd@mwebbiz.co.za

003-112 NPO

I, Celistia Renè Gerber, social worker and Chief Executive Officer of Tygerberg Association for Persons with Physical Disabilities, agree that Mrs. Noreth Muller-Kluits can do research towards a Master's Degree in Social Work at the University of Stellenbosch in partnership with this organization.

#### Services offered:

- Social work services
- Support groups
- Information sharing
- Life skills training
- Awareness programmes
- Talks and exhibitions
- Training opportunities to persons with physical disabilities
- Placement of persons with physical disabilities in the open labour market
- Miracles Protective workshop

The proposed topic will be "SOCIAL SUPPORT NEEDS OF FAMILY CAREGIVERS OF PERSONS WITH PHYSICAL DISABILITIES".

Should any of the research participants need debriefing after the interviews, the service will be available from Tygerberg Association for Persons with Physical Disabilities.

#### Supported by:



Signed at **GOODWOOD** on the **19<sup>th</sup>** day of **JULY 2016**.




Mrs. C. Gerber

**CHIEF EXECUTIVE OFFICER**

**ANNEXURE C**  
**Consent Form for Participants**



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

**STELLENBOSCH UNIVERSITY**  
**CONSENT TO PARTICIPATE IN RESEARCH**

---

The experiences of family caregivers of persons with physical disabilities

You are asked to participate in a research study conducted by Mrs Noreth Muller-Kluits, from the Department of Social Work at Stellenbosch University. The research for dissertation presented in fulfilment of the requirements for the degree of Masters in Social Work.

You were selected as a possible participant in this study because you are a guardian (family caregiver of a person with a physical disability).

**1. PURPOSE OF THE STUDY**

The goal of this study is to gain a better understanding experiences of family caregivers of persons with physical disabilities. This goal would be achieved by means of the following objectives:

- To discuss the experiences of family caregivers of persons with physical disabilities (e.g. financial, emotional, informational).
- To make use of theoretical perspectives that looks at the family environment on different levels (e.g. close relationships, professional support, community support) to explore the different social support needs of family caregivers of persons with physical disabilities.
- To analyse the family caregivers of persons with physical disabilities' experiences from the information gathered from the interviews with participants.
- To make relevant recommendations and suggestions on how to improve social support to family caregivers of persons with physical disabilities

## **2. PROCEDURES**

In preparation for the research study, the organisation would contact possible participants for the research study to determine which of their clients will fit the criteria, are willing to participate in the study. An information sheet regarding the content of the research as well as the contact information of the researcher, will also be given to possible participants. Direct contact can be made with the researcher if needed.

If you volunteer to participate in this study, you would be asked to do the following things:

- Sign this consent form
- Indicate a time and place where researcher can interview you
- Be interviewed regarding your experiences of support needs in taking care of a person with a physical disability (interview is estimated to be between 30-60 min)

## **3. POTENTIAL RISKS AND DISCOMFORTS**

During the interview process, you will be asked to discuss your experiences in taking care of a person with a physical disability. This may cause you to come to terms with difficult experiences which may lead to high emotions. Should you feel the need to discuss these feelings after the interview, you will be referred to Mrs Celista Gerber (the social worker at Tygerberg APD). You can contact her at Tygerberg APD ((w) 021 592 4173).

## **4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

Although there will be no compensation for participants, the research study gives participants the opportunity to voice their experiences and share it. Since there is a lack of previous research on this topic, the research could provide insight to the experiences of family caregivers to put strategies in place to address these issues.

## **5. PAYMENT FOR PARTICIPATION**

No payment will be provided for participation in the study but to minimize expenses to the participants, the researcher will do the interviews at a place comfortable to the participant e.g. participants' homes or the organization (Tygerberg APD).

## **6. CONFIDENTIALITY**

Any information that is given relating to this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality

will be maintained by means of storing the interviews in a locked safe place and all data will be stored in encrypted (password-protected) files.

Although the research will be published for educational or professional purposes, no personal information will be shared or published. Coding of participants (e.g. Participant 1) will be used so to not refer to identifying particulars of the participants. It will further be stressed to refrain from using participants' names in audiotaped interviews. Recordings of interviews will be locked up and erased after five years. Only the researcher and the supervisor will have access to these recordings.

## **7. PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study.

## **8. IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact:

Noreth Muller-Kluits (researcher)

(c) 076 589 5404

Dr I Slabbert (supervisor)

(w) 021 808 2075

Ms Celist Gerber (social worker:

Tygerberg APD)

(w) 021 592 4173

## 9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

### SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me, \_\_\_\_\_, by Mrs Noreth Muller-Kluitsin English and I am comfortable in this language. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

\_\_\_\_\_  
Name of Subject/Participant

\_\_\_\_\_  
Name of Legal Representative (if applicable)

\_\_\_\_\_  
Signature of Subject/Participant or Legal Representative

\_\_\_\_\_  
Date

### SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to \_\_\_\_\_ [*name of the subject/participant*]. He/she was encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used.

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

### INTERVIEW DETAILS

Possible date of interview: \_\_\_\_\_

Planned place of interview: \_\_\_\_\_

Participant contact details: \_\_\_\_\_

**ANNEXURE D**  
**Consent Form for Participants (Afrikaans)**



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY  
jou kennisvenoot • your knowledge partner

**UNIVERSITEIT STELLENBOSCH**  
**INWILLIGING OM DEEL TE NEEM AAN NAVORSING**

---

Ondervindings van familie versorgers van persone met fisiese gestremdhede

U word gevra om deel te neem aan 'n navorsingstudie wat uitgevoer deur Me. Noreth Muller-Kluits, van die Departement van Maatskaplike Werk aan die Universiteit Stellenbosch. Die navorsingstudie sal voorgelê word vir die verkryging van 'n Meestersgraad in Maatskaplike Werk.

U is as moontlike deelnemer aan die studie gekies omdat u 'n familieversorger van 'n persoon met 'n fisiese gestremdheid is.

**1. DOEL VAN DIE STUDIE**

Die doel van die studie is om 'n beter begrip te kry vir die ondervindings van familieversorgers van persone met fisiese gestremdhede. Hierdie doel sal bereik word deur middel van die volgende:

- Om die ondervindings van familieversorgers van persone met fisiese gestremdhede te bespreek.
- Om gebruik te maak van teoretiese perspektiewe om die verskillende maatskaplike ondersteuningsbehoeftes van familieversorgers van persone met fisiese gestremdhede op verskeie vlakke (bv. nabye verhoudinge, professionele ondersteuning, gemeenskapsondersteuning) te verken.
- Om die familieversorgers van persone met fisiese gestremdhede se ondervindinge te analiseer deur gebruik te maak van die inligting wat verkry is tydens die onderhoude.
- Om die relevante aanbevelings te maak oor hoe om maatskaplike ondersteuning vir familie versorger van persone met fisiese gestremdhede te verbeter.

## 2. PROSEDURES

Ter voorbereiding van hierdie navorsingstudie, sal die organisasie potensiële deelnemers, wat voldoen aan die kriteria, kontak om uit te vind wie gewillig sal wees om deel te wees van die navorsingstudie. 'n Inligtingsblad met die inhoud van die navorsing sowel as die kontakbesonderhede van die navorser, sal vir potensiële deelnemers gegee word. Direkte kontak kan met die navorser gemaak word indien nodig.

Indien u inwillig om aan die studie deel te neem, sal daar gevra word dat u die volgende moet doen:

- Onderteken hierdie inwilligheidsvorm
- Dui aan watter tyd en plek die onderhoud kan gedoen word deur die navorser
- Onderhoud word gevoer met deelnemer oor hul ondervinding van die ondersteuningsbehoeftes van persone met fisiese gestremdhede (onderhoud sal ongeveer 30-60 minute duur)

## 3. MOONTLIKE RISIKO'S EN ONGEMAKLIKHEID

Tydens die onderhoudproses, sal u gevra word om u ondervindings te deel in die versorging van 'n persoon met 'n fisiese gestremdheid. Dit mag daartoe lei dat u uself moet vergewis met moeilike ervarings wat u moes deurmaak wat tot emosionele gevoelens mag lei. Indien u voel u moet hierdie gevoelens met iemand bespreek, sal u verwys word na die maatskaplike werker by Tygerberg APD.

## 4. MOONTLIKE VOORDELE VIR PROEFPERSONE EN/OF VIR DIE SAMELEWING

Alhoewel daar geen betaling is vir deelnemers van die studie nie, sal die navorsingstudie deelnemers die geleentheid gee om hul ervarings en bekommernisse te deel. Omrede daar 'n gebrek aan navorsing is op hierdie onderwerp, kan die navorsing ook moontlike begrip gee vir die ervarings van familieversorgers ten einde strategieë in plek te sit om die probleme aan te spreek.

## 5. VERGOEDING VIR DEELNAME

Geen betaling sal gegee word aan enige deelnemer nie, maar ten einde die kostes vir deelnemers te verminder, sal die navorser die onderhoude doen op 'n tyd en plek wat die deelnemers verkies bv. deelnemers se huise of die organisasie (Tygerberg APD).

## 6. VERTROULIKHEID

Enige inligting wat deur middel van die navorsing verkry word en wat met u in verband gebring kan word, sal vertroulik bly en slegs met u toestemming bekend gemaak word of soos deur die wet vereis. Vertroulikheid sal gehandhaaf word deur onderhoude in 'n kluis en alle data in 'n lêer met 'n geheime kode, te stoor.

Alhoewel die navorsing gepubliseer sal word vir opvoedkundige of professionele redes, sal geen persoonlike inligting gepubliseer of gedeel word. Daar sal gebruik gemaak word van kodes (bv. Deelnemer 1) om deelnemers te identifiseer sonder om hul persoonlike inligting te gebruik. Daar sal verder gepoog word om nie die naam van die deelnemer in die klankbaan opgeneemde onderhoude te noem nie. Die opnames van die onderhoude sal in 'n kluis gestoor word en vernietig word na vyf jaar. Slegs die supervisor en die navorser sal toegang hê tot hierdie opnames.

## **7. DEELNAME EN ONTTREKKING**

U kan self besluit of u aan die studie wil deelneem of nie. Indien u inwillig om aan die studie deel te neem, kan u te eniger tyd u daaraan onttrek sonder enige nadelige gevolge. U kan ook weier om op bepaalde vrae te antwoord, maar steeds aan die studie deelneem.

## **8. IDENTIFIKASIE VAN ONDERSOEKERS**

Indien u enige vrae of besorgdheid omtrent die navorsing het, staan dit u vry om in verbinding te tree met:

Noreth Muller-Kluis (navorser)

(s) 076 589 5404

Dr I Slabbert (supervisor)

(w) 021 808 2075

Ms Celist Gerber (maatskaplike werker:

Tygerberg APD)

(w) 021 592 4173

## **9. REGTE VAN PROEFPERSONE**

U kan te eniger tyd u inwilliging terugtrek en u deelname beëindig, sonder enige nadelige gevolge vir u. Deur deel te neem aan die navorsing doen u geensins afstand van enige wetlike regte, eise of regsmiddel nie. Indien u vrae het oor u regte as proefpersoon by navorsing, skakel met Me. Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] van die Afdeling Navorsingsontwikkeling, Universiteit Stellenbos



**VERKLARING DEUR PROEFPERSOON OF SY/HAAR  
REGSVERTREENWOORDIGER**

Die bostaande inligting is aan my, \_\_\_\_\_, gegee en verduidelik deur Me. Noreth Muller-Kluits in Afrikaans en ek is dié taal magtig. Ek is die geleentheid gebied om vrae te stel en my vrae is tot my bevrediging beantwoord.

Ek wil hiermee vrywillig in om deel te neem aan die studie. Ek is 'n kopie van hierdie vorm gegee.

\_\_\_\_\_  
**Naam van proefpersoon/deelnemer**

\_\_\_\_\_  
**Naam van regsverteenvoordiger (indien van toepassing)**

\_\_\_\_\_  
**Handtekening van proefpersoon/deelnemer of regsverteenvoordiger**

\_\_\_\_\_  
**Datum**

**VERKLARING DEUR ONDERSOEKER**

Ek verklaar dat ek die inligting in hierdie dokument vervat verduidelik het aan \_\_\_\_\_  
[naam van die proefpersoon/deelnemer]. Hy/sy is aangemoedig en oorgenoeg tyd gegee om vrae aan my te stel. Dié gesprek is in Afrikaans gevoer en geen vertaler is gebruik nie.

\_\_\_\_\_  
**Handtekening van onderzoeker**

\_\_\_\_\_  
**Datum**

**ONDERHOUD BESONDERHEDE**

Moontlike datum van onderhoud:

\_\_\_\_\_

Beplande plek van onderhoud:

\_\_\_\_\_

Deelnemer se kontakbesonderhede:

\_\_\_\_\_

**ANNEXURE E**  
**Example of Questionnaire**



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

**UNIVERSITY OF STELLENBOSCH**  
**DEPARTMENT OF SOCIAL WORK**

**The experiences of family caregivers of persons with physical disabilities**

Interviewer: Noreth Muller-Kluits  
Dissertation for M in Social Work

*All the information recorded in this questionnaire will be regarded as confidential.*

---

**PARTICIPANT NUMBER:** \_\_\_\_\_

**INTERVIEW DATE:** \_\_\_\_\_

**1. IDENTIFYING PARTICULARS**

**1.1 Gender**

Male	<input type="text"/>
Female	<input type="text"/>
Other	<input type="text"/>

**1.2 Marital Status**

Single	<input type="text"/>
Married	<input type="text"/>
In long-term relationship	<input type="text"/>
Widowed	<input type="text"/>
Divorced	<input type="text"/>
Other	<input type="text"/>

**1.3 Employment status**

Working full-time	<input type="text"/>
Working part-time	<input type="text"/>
Self-employed	<input type="text"/>
Unemployed	<input type="text"/>
Retired	<input type="text"/>

**1.4 Age of participant**

21 to 30 years	<input type="text"/>
31 to 40 years	<input type="text"/>
41 to 50 years	<input type="text"/>
51 to 60 years	<input type="text"/>
60 years and older	<input type="text"/>

**1.5 What area (suburb) in Cape Town do you stay in?**

**1.6 Number of children or other family members with disability**

One child

Two children

More than three children

Other family member:

Specify

Other family member and child/-ren: Specify


**1.7 Type of physical disability of family member**

Visual impairment

Hearing impairment

Spinal Cord Injury

Amputation

Cerebral Palsy

Other: Specify


**1.8 Age of family member with disability**

0-5 years

6-12 years

13-18 years

19-30 years

31-50 years

50 + years


**1.9 What onset of physical disability**

Congenital disability

Acquired (after birth)


## **2. RESOURCES AND SOCIAL SUPPORT**

**2.1 Resources and support services received:**

*2.1.1 What type of health care system (public or private) do you and your family make use of?*

*2.1.2 What are your experiences of the health services you have received?*

**2.2 Resources and support services needed:**

*2.2.1 What support services do you still need in order to take care of your family member with a disability?*

## **3. RESOURCES AND SOCIAL SUPPORT ACCORDING TO BRONFENBRENNER'S MODEL**

**3.1 Microsystem**

*3.1.1 Do you have opportunities to interact with other persons with family member/-s with physical or other disabilities? Please elaborate.*

3.1.2 *What is your experience of the accessibility of your home to your family member/-s with a physical disability?*

3.1.3 *What support do you need to make improvements to make to your home more accessible?*

### **3.2 Mesosystem**

3.2.1 *What professionals (e.g. educators or health professionals) do you interact with in your community to assist in caring for your family member/-s with a physical disability?*

3.2.2 *What are your experiences regarding the support you received from professionals?*

### **3.3 Exosystem**

3.3.1 *What community facilities (e.g. clinics) are you currently using in order to assist with caring for your family member/-s with a physical disability?*

3.3.2 *What are your experiences regarding the support that you are currently receiving from the community facilities?*

3.3.3 *What is your experience of the accessibility of your community (buildings and in general) to your family member/-s with a physical disability?*

3.3.4 *Any suggestions on what changes in services or resources are needed to better service delivery to persons with disabilities and their families within the community e.g. regarding accessibility and facilities?*

### **3.4 Macrosystem**

3.4.1 *Are you aware of any policies and legislation that could support persons with physical disabilities and their families? Please elaborate.*

## **4. EXPERIENCES RELATED TO THE STAGES OF GRIEF AS WELL AS OTHER EMOTIONS (POSITIVE AND NEGATIVE)**

4.1 **Which emotion describes your feelings best, when you first found out your family member/-s has/had a disability?**

4.2 **Briefly describe your first response when you found out your family member/-s has/had a disability?**

## **5. CAREGIVER BURDEN, BARRIERS AND COPING MECHANISMS**

5.1 **Besides yourself, who else takes care of family member/-s with disability?**

5.2 **What would you say are some of the biggest challenges that you and your family has faced in caring for your family member/-s with a physical disability?**

**5.3 What coping mechanisms have you used in caring for your family member/-s with a physical disability?**

**5.4 How has having a family member/-s with a physical disability impacted on your life?**

**6. ANY OTHER COMMENTS OR OTHER CONTRIBUTIONS**

*Thank you for participating in the research study*

**ANNEXURE F**  
**Example of Questionnaire (Afrikaans)**



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
 jou kennisvennoot • your knowledge partner

**STELLENBOSCH UNIVERSITEIT**  
**DEPARTEMENT VAN MAATSKAPLIKE WERK**

**DIE ONDERVINDINGE VAN FAMILIEVERSORGERS VAN PERSONE  
 MET FISIESE GESTREMDHEDE**

Onderhoudvoerder: Noreth Muller-Kluits  
 Tesis vir M in Maatskaplike Werk

*Al die informasie opgeneem in hierdie vraelys sal vertroulik hanteer word*

**DEELNEMER NOMMER:** \_\_\_\_\_

**ONDERHOUD DATUM:** \_\_\_\_\_

**1. IDENTIFISERENDE BESONDERHEDE**

**1.1 Geslag**

Manlik	<input type="text"/>
Vroulik	<input type="text"/>
Ander	<input type="text"/>

**1.2 Huwelikstatus**

Enkellopend	<input type="text"/>
Getroud	<input type="text"/>
Langtermyn verhouding	<input type="text"/>
Weduwee/Wewenaar	<input type="text"/>
Geskei	<input type="text"/>
Ander	<input type="text"/>

**1.3 Werkstatus**

Werk voltyds	<input type="text"/>
Werk deelyds	<input type="text"/>
Werk vir self	<input type="text"/>
Werk nie tans	<input type="text"/>
Afgetree	<input type="text"/>

**1.4 Ouderdom van deelnemer**

21 tot 30 jaar	<input type="text"/>
31 tot 40 jaar	<input type="text"/>
41 tot 50 jaar	<input type="text"/>
51 tot 60 jaa	<input type="text"/>
61 jaar en ouer	<input type="text"/>

**1.5 In watter area (voorstad) bly u in Kaapstad?**

**1.6 Aantal kinders of ander familie-lede met 'n fisiese gestremdheid**

Een kind	
Twee kinders	
Meer as drie kinders	
Ander familie-lid	
Spesifiseer	
Ander familie-lid en kind	
Spesifiseer	

**1.7 Tipe fisiese gestremdheid van familielid**

Visuele gestremdheid	
Gehoor gestremdheid	
Rugmurgbesering	
Amputasie	
Serebrale gestremdheid	
Ander: Spesifiseer	

**1.8 Ouderdom van familielid met gestremdheid**

0-5 jaar	
6-12 jaar	
13-18 jaar	
19-30 jaar	
31-50 jaar	
50+ jaar	

**1.9 Watter tipe ontstaan het die gestremdheidg gehad**

Met geboorte	
Na geboorte	

## **2. HLPBRONNE EN MAATSKAPLIKE ONDERSTEUNING**

### **2.1 Hulpbronne en Maatskaplike Ondersteuning ontvang:**

*2.1.1 Watter tipe gesondheidsdienste gebruik u en u familie?*

*2.1.2 Wat is u ondervinding in verband met die ondersteuningsdienste wat u ontvang?*

### **2.2 Hulpbronne en Ondersteuningsdienste benodig:**

*2.2.1 Watter ondersteuningsdienste benodig u steeds in die versorging van u familielid/-lede met gestremdheid?*

## **3. HULPBRONNE EN MAATSKAPLIKE ONDERSTEUNING VOLGENS BRONFENBRENNER SE MODEL**

### **3.1 Mikrosisteem**

*3.1.1 Het u enige geleenthede om met ander persone met familieledes met gestremdhede te sosialiseer? Motiveer.*

*3.1.2 Wat is u ondervinding in verband met die toeganklikheid van u huis vir u familielid/-lede met 'n fisiese gestremdheid?*

- 3.1.3 *Watter ondersteuning nodig u steeds om u huis meer toeganklik te maak?*

### **3.2 Mesosisteem**

- 3.2.1 *Watter professionele persone (bv. opvoeders of gesondheidspersoneel) gebruik u binne u gemeenskap ten einde u te ondersteun in die versorging van u familielid/-lede met 'n fisiese gestremdheid?*
- 3.2.2 *Wat is u ondervinding ten opsigte van die ondersteuning wat u ontvang het van professionele persone?*

### **3.3 Eksosisteem**

- 3.3.1 *Watter gemeenskapsfasiliteite (bv. klinieke) gebruik u tans ter ondersteuning van u versorging van u familielid/-lede met 'n fisiese gestremdheid?*
- 3.3.2 *Wat is u ondervinding ten opsigte van die ondersteuning wat u tans ontvang van gemeenskapsfasiliteite?*
- 3.3.3 *Wat is jou ondervinding ten opsigte van die toeganklikheid van u gemeenskap (geboue en in die algemeen) vir u familielid met 'n fisiese gestremdheid?*
- 3.3.4 *Enige voorstelle op watter veranderinge aangebring kan word in die dienste en hulpbronne in die beter dienslewering vir persone met gestremdhede en hul families binne u gemeenskap bv. toeganklikheid van fasiliteite?*

### **3.4 Makrosisteem**

- 3.4.1 *Is u bewus van enige beleide of wetgewings ter ondersteuning van persone met fisiese gestremdhede en hul families? Spesifiseer.*

## **4. ONDERVINDINGS TEN OPSIGTE VAN DIE VERSKILLENDE FASES VAN ROU SOWEL AS ANDER EMOSIES**

- 4.1 **Watter emosie beskryf u gevoelens die beste toe u vir die eerste keer uitvind u familielid/-lede het 'n gestremdheid?**
- 4.2 **Beskryf kortliks u eerste reaksie toe u uitvind u familielid/-lede het 'n gestremdheid?**

## **5. VERSORGERSDRUK, STRUIKELBLOKKE EN HANTERINGSMECHANISMES**

- 5.1 **Buiten uself, wie anders versorg u familielid/-lede met gestremdheid?**
- 5.2 **Wat sal u sê is die grootste uitdagings wat u en u familie ondervind in die versorging van u familielid/-lede met 'n fisiese gestremdheid?**
- 5.3 **Watter hanteringsmeganismes het u al gebruik in die versorging van u familielid/-lede met gestremdheid?**



**5.4 Hoe het die versorging van u familielid met 'n fisiese gestremdheid u lewe beïnvloed?**

**6. ENIGE ANDER KOMMENTAAR OF BYDRAES?**

*Baie dankie vir u deelname aan my navorsing*

**ANNEXURE G**  
**Research Information Sheet (Afrikaans/English)**

**NAVORSING INLIGTINGSBLAD**

**Ondervindings van familie versorgers van persone met  
fisiese gestremdhede**

(navorsing vir M in Maatskaplike Werk, Universiteit Stellenbosch)

**Navorser:**

Me Noreth Muller-Kluis in samewerking met Tygerberg APD  
(kontakpersoon: Me C Gerber)

**Datum vir voorgestelde onderhoude:**

April 2017

**Bepaalde plek vir onderhoude:**

Tygerberg APD kantoor/deelnemer se huis

**Aard van onderhoude:**

Ongeveer 60 min oop- en geslote vrae wat audio opgeneem sal word (na die deelnemer(s)  
se ondertekende toestemming)

**Opsomming van navorsing doel:**

Amper almal sal een of ander vorm van gestremdheid ervaar (of tydelik of permanent) in hul lewens. Verskeie vorms van gestremdheid kan gebeur – ouers wat uitvind hul baba het Down Syndrome, 'n soldaat wat sy been verloor in oorlog of 'n persoon wat 'n beroerte gehad het.

Verskeie vorige navorsingstudies het al op die behoeftes van persone met gestremdhede gefokus. Hierdie studies al egter fokus op die behoeftes van familieversorgers van persone met fisiese gestremdhede, weens die gebrek aan vorige navorsing.

Gestremdheid in 'n kind beïnvloed nie net die kind nie, maar die hele familie. Daar is eers onlangs begin fokus op die behoeftes van familie. Ouers, professionele persone en akademiese navorsers het al klem gelê daarop dat families van kinders met gestremdhede, unieke behoeftes het.

Hierdie navorsing se oorsprong kom van die navorsingsvraag – *Wat is die maatskaplike ondersteuningsbehoefte van familie versorgers van persone met fisiese gestremdhede?* Die doel van die studie is om 'n beter begrip te verkry vir die ondersteuningsbehoefte van familieversorgers van persone met gestremdhede. Dit sal familieversorgers die geleentheid gee om hul ondervindings en voorstelle vir verbeterde dienslewering, te deel.

*Dankie vir u ondersteuning*

# RESEARCH INFORMATION SHEET

## Experiences of family caregivers of persons with physical disabilities

(research for fulfilment of M in Social Work, University of Stellenbosch)

### Researcher:

Mrs Noreth Muller-Kluits in collaboration with Tygerberg APD  
(contact person: Mrs C Gerber)

### Date of interview(s) intended:

April 2017

### Place/Venue of interview(s) intended:

Tygerberg APD office/participant's home

### Nature of interviews:

Approximately 60 min of open- and closed-ended questions that will be audio-recorded  
(after signed consent of the participant(s))

### Summary of research objective:

Almost everyone will experience a form of impairment or disability (either temporary or permanent) in their life time. Various forms of impairment could happen at any given moment for example parents finding out their baby is born with Down syndrome, a soldier that loses his leg at war or a person who suffered a stroke and left paralysed on the one side.

Many previous research studies investigated the needs of persons with disabilities. This study will focus on the needs of the family caregivers of persons with physical disabilities due to lack of sufficient previous research.

Disability in a child not only affects the child but also impacts on the child's family. Only recently did the focus of services expand to the needs of families living with a child with disability. Parents, professionals as well as academic researchers have claimed that families of children with disabilities face unique needs as a result of their children's disabilities.

The study originates from the research question - *What are the social support needs of family caregivers of persons with physical disabilities?* The goal of this study is to gain a better understanding of the support needs of family caregivers of persons with disabilities. It will give family caregivers the opportunity to discuss their experiences and suggestions to improve service delivery to families of persons with physical disabilities.

*Thank you for your support*

**ANNEXURE H**  
**Example of Member Checking Verification (English/Afrikaans)**

Participant Number

I hereby declare that I have read the transcribed interview done for this research study:

Yes

No

I hereby declare that I agree with the content of the transcribed interview:

Yes

No

OR/OF

Deelnemer Nommer

Ek verklaar hiermee dat ek die transkribeerde onderhoud vir die navorsing gelees het:

Ja

Nee

Ek verklaar hiermee dat ek saamstem met die inhoud van hierdie getranskribeerde onderhoud:

Ja

Nee

## ANNEXURE H

### Independent Code Theme Verification

I hereby declare that I have read the transcribed interviews done for this research study:

Yes

X

No

THEMES	SUB-THEMES	CATEGORIES
<b>Theme 1:</b> Support services used	Sub-theme 1.1.: Microsystem	a) Parental subsystem b) Spousal subsystem c) Sibling subsystem
	Sub-theme 1.2.: Mesosystem	a) Extended family b) Friends c) Professionals
	Sub-theme 1.3.: Exosystem	a) Educational institutions b) Health facilities c) Welfare organisations and other community facilities
	Sub-theme 1.4.: Macrosystem	a) South African health care system b) Education system c) Disability benefits
<b>Theme 2:</b> Support needs	Sub-theme 2.1.: Microsystem	
	Sub-theme 2.2.: Mesosystem	
	Sub-theme 2.3.: Exosystem	a) Lack of schools b) Lack of long-term care centres c) Overcrowded health care facilities d) Lack of public transport e) Recreational groups for PwD f) Lack of information
	Sub-theme 2.4.: Macrosystem	a) Policies and legislation b) Disability-friendly employment
<b>Theme 3:</b> General experiences of family caregivers	Sub-theme 3.1.: Feelings of grief	
	Sub-theme 3.2.: General positive experiences	
	Sub-theme 3.3.: General negative experiences	
<b>Theme 4:</b> Barriers experienced by family caregivers	Sub-theme 4.1.: Lack of support	a) Community accessibility and safety b) Access to service c) Lack of professional support
	Sub-theme 4.2.: Caregiver burden issues	a) Physical health issues b) Personal isolation c) Lack of respite services d) Employment issues of caregivers e) Financial issues f) Emotional health issues g) Giving up on own aspirations (caregiver)
	Sub-theme 4.3.: General issues with PwD	a) Behavioural issues b) Being blamed by PwD
<b>Theme 5:</b> Coping mechanisms of family caregivers	Sub-theme 5.1.: Outings	
	Sub-theme 5.2.: Recreational activities	
	Sub-theme 5.3.: Socialising	
	Sub-theme 5.4.: Personal time	

I hereby declare that I agree with the above-mentioned themes, sub-themes and categories for this research study:

Yes

X

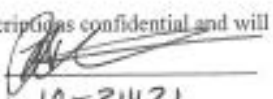
No

I will keep the content of the transcription as confidential and will not disclose any identifying information.

Signature:

SACSSP number:

Date:

  
10-31421  
23-08-2017

**ANNEXURE I**  
**Declaration of language practitioner**

---

Ella Belcher  
Language Editor and Translator  
22 Bruton Place  
Heldervue  
Somerset West

Member of the South African Translators' Institute  
Member of the Professional Editors' Group  
☎ +27+21-8550673    ☎ 083 294 8393  
Postal address: P.O. Box 12570 Die Boord 7813 South Africa

---

**DECLARATION**

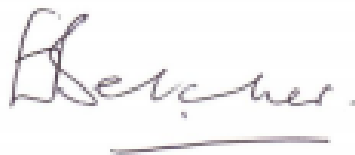
I hereby certify that the Master's thesis mentioned below has been properly language edited. The author was responsible for the correctness of the references and the reference list. The annexures have not been edited, as per the author's instructions.

**Title of thesis**

‘The experiences of family caregivers of persons with physical disabilities’

**Student**

Noreth Muller-Kluis



ELLA BELCHER  
Somerset West  
23 August 2017